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Surviving, thriving and being outside:  
applying the capabilities approach to reconceptualise  
the social justice experiences of people with mental  
distress

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## Abstract

The empirical evidence associating people with mental distress and social injustice is unequivocal. This thesis offers a least reductive, structured qualitative exploration of how different social justice outcomes for people in this social group happen. To achieve this the study explores whether and how the capabilities approach can be applied to provide a normative means of explaining the social justice experiences of people with mental distress. It does this through conducting and analysing individual interviews with twenty-two people living in Glasgow who have recent in-patient experience of psychiatric hospital, sixteen participants being interviewed twice. The interviews are framed by combining concepts from the capabilities approach with relevant sociological literature, seeking to: understand the relationship between personal, social and structural factors affecting lived experiences; consider the character of social justice experienced and conceptualise this using concepts from the capabilities approach; take a critical realist approach to understanding how social justice experiences may be produced and reproduced; pursue these aims with regard to both values-based research principles from the survivor-influenced literature and participation principles from the capabilities approach.

By critically interpreting empirical data using capabilities concepts and sociological concepts, the analysis is able to combine what had been two separate fields of study (Holmwood, 2013) and provide an original interpretation of how social injustice tends to be reproduced. The substantive findings explain how different social justice outcomes for people with mental distress are shaped by living with mental distress, experiencing the psychiatric system, and living in society. Although participants tend to have characteristics of ‘surviving’, or living with ongoing social injustice, a minority have characteristics of thriving. Some participants within both characteristic groups also experience ‘being outside’ dominant social norms. Methodologically the study demonstrates that concepts central to capabilities such as Conversion Factors and the domains approach can be operationalised to explain social justice outcomes for this social group, adding to and critiquing these concepts in the process. Theoretically, the thesis proposes a nascent critical capabilities model of mental distress, reinforcing the compatibility between the capabilities approach and critical realism, so providing a further contribution to the sociology of mental distress.

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Any mistakes remaining in this thesis are all my own work.



## **Author's Declaration**

I declare that, except where explicit reference is made to the contribution of others, that this thesis is the result of my own work and has not been submitted for any other degree at the University of Glasgow or any other institution.

Richard Brunner

16 April 2015

# 1 Introduction

Over a century of biomedical dominance of understandings of mental distress and consequent systems of treatment have produced multiple changes in diagnostic classifications, generations of medications, regular reframing of laws, and shifts from long-stay asylums to community care, and from care and support to 'recovery'. Yet despite this century of ostensibly exhaustive change, people with mental distress continue to experience high levels of social injustice. And beneath this, social inequalities continue to influence experience of mental distress (Marmot, 2010; Allen et al, 2014).

This sociological thesis offers a least reductive, structured qualitative exploration of how different social justice outcomes for people with mental distress happen, aiming, paraphrasing Beresford (2010, p.57), to reconceptualise mental distress within a social framework. This reconceptualisation is sought through exploring the utility of the capabilities approach as a normative means to understand the lived experiences of people with mental distress, framing this within a critical realist epistemology. In doing this the study makes an original contribution both to the capabilities approach and to the sociology of mental distress.

The theme of this study has both academic and personal interest for me. I have some personal experience of mental distress but not of using the mental health system, on which I reflexively expand in the methodology chapter. I also have professional experience of working with and alongside people with mental distress including within the mental health system. In the 1990s I worked as a support worker with people with diagnoses of mental distress and experiences of homelessness. I then worked for three years as an advocate for mental health service users in an East London psychiatric hospital. As a support worker I experienced the individuality of people with mental distress and the complexity of barriers to their social justice. In the context of the psychiatric hospital I was witness to the hierarchies of psychiatric power, the practices of medication-first treatment, diagnosis by trial and error, the stressful conditions in which people in hospital existed, the subjective pain and unease that people with mental distress can experience, the social injustice of people being discharged back into the same social circumstances only to return to hospital, and the limitations of

advocacy and the law in enabling patients to have their voices heard and liberties upheld. So personal and professional interests have combined in this study which uses qualitative methods to enable the diverse perceptions and experiences of a sample of people with mental distress to be articulated and applies a normative-ethical framework for analysis of this data, with the overarching aim of achieving a study which may contribute to explaining and ending the social injustices experienced by this social group.

As a research field, the sociology of mental distress has developed significantly over the past century as it has sought to 'problematize the notion of mental disorder' (Rogers and Pilgrim, 2010, p.19). Fields of study have included structuralist studies (e.g. Foucault, 1967), symbolic interactionist and social constructivist studies (e.g. Goffman, 1963; Scheff, 1966), and survivor-influenced studies (e.g. Coles et al, 2013).

However, Busfield has identified a need for 'careful, theoretically informed empirical work' in relation to the sociology of mental distress, including on 'the epistemological and ontological assumptions on which sociological work on mental disorder is grounded' (2001, p.12). She has detected gaps in relation to sociological understandings of mental distress, including in exploration of the 'complexity, subtlety and diversity of disabling barriers' and of 'the social location of the individual and their perceptions of the significance of their mental health problems in terms of their wider life experiences' (2001, p.44). Howell and Voronka (2012, p.2) have argued that empirical studies should acknowledge the barriers faced by people with mental distress and their denial of social justice:

Approaching mental health through a social justice lens can reveal rich connections that highlight some of the most important themes in social justice research: inclusion, power, recognition, political economy, difference, equity and rights. And yet, the richness of this area of research has not been fully explored by social justice studies.

Harper and Speed have reinforced (2012, p.21) that, in understanding 'individual survivor narratives ... more socially just frameworks are required, more fully grounded in everyday experience' to avoid appropriation by 'professionally derived conceptual frameworks'. Tew et al (2006) have proposed five principles

as a value base for mental health research that aims to respect the values, aspirations and concerns of service users.

This study pushes at these sociological gaps by seeking to understand the social justice experiences of people with mental distress who have been in psychiatric hospital in the recent past and who currently live in the community. Few sociological studies have conducted in-depth qualitative analysis of the social justice experiences of people with mental distress living in the community as an aim in itself, despite, as Tew et al (2006, p.12) have noted:

Now that the majority of mental health care is delivered in community, rather than hospital settings, the need for research to recognise the complex interplay of social, psychological, economic, political and environmental factors on an individual's mental well-being is ever more vital.

The most effective of these types of study have critically accepted the material personal experience of mental distress whilst developing critiques of the psychiatric system and analysing agency/structure relations, in order to develop critiques of substantive and formal theory (e.g. Barham and Hayward, 1991; Parr, 2008). They have highlighted practical questions about how social justice may be achieved for people with mental distress whilst raising ontological and epistemological challenges for society about how social justice is understood for people with mental distress, in the process providing a commentary on the organisation of society as a whole. They have also raised challenging questions for people with mental distress themselves, for whom the medical model may be 'the only conceptual framework they have ever known' (Beresford, 2002, p.582). As Silverman (2005, pp.97-98) has argued, models '...tell us what reality is like and the basic elements it contains ('ontology') and what is the nature and status of knowledge ('epistemology')'. This is particularly significant in this context as the ways in which people with mental distress are understood and treated medically and socially have been profoundly affected by the underpinning model used (Tyrer and Steinberg, 2006).

So the normative aim of this study is, whilst critiquing dominant medicalised constructions of mental distress, to enhance social justice outcomes of people

with mental distress. This reflects Sayer's argument for a critical social science (2009, p.775):

In practice, the targets of the critiques developed by substantive CSS are not merely false ideas and their supports and consequences, or lack of freedom, but injustices and avoidable suffering.

Sayer argues that in conducting explanatory critique, critical social science must combine facts and values. He suggests that this might be achieved through (2009, p.781):

...a closer engagement between social science and the sustained, patient deliberation on forms of judgement and their legitimacy provided by lay ethical thought and by moral and political philosophy.

Sayer proposes the capabilities approach (Sen, 1980) as a framework for developing this normative-evaluative essence of critical social science. The capabilities approach is not a full theory of justice but can describe and conceptualise dimensions of justice (Sen, 2010, pp.296-298; Nussbaum, 2006, pp.75-76; Venkatapuram, 2011, pp.125-130) from the starting point of evaluating 'what people are actually able to do and to be' (Nussbaum, 2006, p.70). It does this normatively, accounting for the state in which a person is actually living (functioning) and their practical opportunity (capability) to make alternative choices from a capability set. It has an integral focus on agency, a core issue for people with mental distress (Davidson et al, 2009), and a concern for participation by groups experiencing injustice in judging what are substantive and valued capabilities.

This study follows Sayer's proposition by using the capabilities approach as a methodological tool and analytical framework to evaluate the lived experiences of people with mental distress, seeking both to conceptualise their social justice outcomes using this framework and with the normative aim of reducing their suffering and increasing their flourishing. Or, as Hopper (2007, p.875) notes, it 'will worry about what enables people to thrive, not simply survive'.

Even accounting for the poor reliability and validity of psychiatric diagnoses (Busfield, 2011) macro-level evidence suggests that people with mental distress in the UK experience social injustice (Office of the Deputy Prime Minister, 2004).

However, beneath this, micro-level social justice outcomes will vary. This study uses a two-stage individual interview process with a sample of people living in Glasgow and with recent experience of being in psychiatric hospital, aiming to ensure that the voices of people with mental distress are clearly heard. It interprets what people have to say using an originally developed sociologically informed capabilities framework, seeking to draw out explanatory factors for social justice outcomes at personal, social and structural levels.

The capabilities approach has been applied to disabled people (e.g. Burchardt, 2004; Kuklys, 2005; Mitra, 2006), women, and people in poverty around the globe, framing how social justice for these groups is understood. But people with mental distress have been left aside from this, and only now are theoretical and empirical analyses emerging that apply the capabilities approach to lived experience of mental distress (see Chapter three). Martha Nussbaum, alongside Amartya Sen one of the two prime instigators of the capabilities approach, concurs that this is a gap that requires addressing (personal correspondence, 26 May 2014):

I agree about the neglect of mental illness in the capabilities literature, and I have contributed to that neglect by focusing on cognitive disability. I hope your work will help address this lack.

## **1.1 A capabilities definition of social justice**

In the capabilities literature, Venkatapuram (2011, p.20) conceptualises what he calls health justice as having the ‘abilities to be and do things that make up a minimally good, flourishing and non-humiliating life for a human being in the contemporary world’. Venkatapuram provides an ethical definition, not a disease-based or medical definition, the moral claim being to the capability, into which he is able to build explanation of health justice outcomes through four determinants: biological endowments and needs, individual behaviours, physical environment and social conditions (2011, p.19). His definition is capacious, focusing on what people can actually do and be, whilst enabling a normative judgment of both outcomes and of agency within those outcomes. The key evaluative judgments made in Venkatapuram’s definition are relational and with an understanding of flourishing but also based on an understanding of a minimum threshold. His integration of explanatory determinants is compatible

with the wider literature on social determinants of mental distress (e.g. Tew, 2011, Ch.3), further explicated in chapter two below, whilst also providing a critique of the limits of capabilities in explaining the roots of social injustice, explored in chapter three.

Lewis (2012) in one of the few qualitative UK papers exploring capabilities and mental distress uses capabilities to focus the judgment of 'mental health' to be made on the basis of what a person is capable of doing and being: again, a moral claim to the capability. She operationalises mental health as: 'what you are able to be, do and achieve and how you feel' (2012, p.526) which, whilst similar to Venkatapuram, incorporates a stronger subjective dimension, 'how you feel' close to subjectivist accounts of wellbeing critiqued by Sen (2010, pp.273-275) due to their lack of account of adaptive preferences and their reductionism. But the claims of Venkatapuram and Lewis are also too narrow. Their definitions are both much broader than that of 'health justice' or 'mental health'; their definitions are actually capabilities definitions of social justice, which may be achieved whilst experiencing material, subjective mental distress in Lewis' case, or ill-health in Venkatapuram's case. To view them as definitions of health justice or of mental health is too narrow.

The capabilities understanding of social justice used in the thesis is informed by the foundational work of Nussbaum. In contrast to Sen (Venkatapuram, 2011, p.29), and founded on her critiques of other approaches to social justice within the liberal tradition (notably that of Rawls e.g. 2003, p.50; 2006; 2011), Nussbaum has argued that her version of the capabilities approach, expanded further in Chapter three, and involving delivering ten capabilities to all citizens, constitutes a 'minimal account of social justice' (2006, p. 71; see also 2011, ch.2). It is this minimally sufficient conception of social justice which this thesis follows throughout, comparable in its sufficiency to Venkatapuram's moral claim to a 'minimally good, flourishing and non-humiliating life' in his conceptualisation of health justice (2011).

To answer the research questions for this study (Section 1.3), the conception of social justice is necessarily related to the lived experiences of the individual participants. This is consistent with the research design and individual interview method, and follows the methodological approach of previous qualitative

sociological studies with this population group, including studies that have used capabilities as a social justice framework to explore individual lived experiences (e.g. Benbow et al, 2014); and that have interpreted individual experiences using: conflict theory and moral theory (e.g. Barham and Hayward, 1991); theories of social inclusion and geographies of difference (Parr, 2008); and social integration (Ware et al, 2007). This approach, using individuals-as-ends, also enables avoidance of the problem of aggregate capabilities, highlighted by Venkatapuram (2011, pp.211-212). It is consistent with Nussbaum's argument that capabilities 'belong first and foremost to individual persons, and only derivatively to groups' (2011, p.35).

Considering individuals-as-ends experiencing social justice does not mean that social justice is treated in this study as an individualised concept. Social justice will always, by definition, have social claims and is treated as a relational concept throughout the study. For Zimmerman (2006) the sociological operationalisation of capabilities in qualitative studies provides the opportunity to focus on the 'relation between individual aptitudes and social opportunities' (2006, p.473). The present study follows this by using a relational analysis to understand what people with mental distress 'are actually able to do and be' (Nussbaum, 2006, p.70), understanding, consistently with research question one (Section 1.3) and the sociological context of the study (Chapter two) that social justice outcomes are shaped in multiple, contingent, and layered ways. The methodological approach explores this further (Chapter four).

The notion of social justice being evaluated in relation to individual experiences also does not mean that those individuals are seen as 'possessing' social justice; social justice is always relational. Rather, it suggests that the concept of social justice can in the end be judged on an individual level, which this analysis does; and the analysis uses a capabilities framework, additionally informed by sociological constructs, to make judgments beyond the subjective, again explained further in the methodology (Chapter four).

This analytical process highlights an epistemological problem featured in a large body of capabilities literature. Theoretical and normative work using capabilities as an analytical framework persistently applies notions of social justice to



individuals-as-ends (e.g. Sen, 1980; Nussbaum, 2003; Venkatapuram, 2011). For example, Venkatapuram (2011, p.23) states: 'I ground the entitlement to a health capability in our shared values of human freedom and in showing respect for every human being: both these values are central components or 'rock bottom' values of liberal social justice'. Nussbaum (2003, p.40), whose minimal account of social justice this thesis follows, explicitly extends the account of social justice to individuals as ends: '...the capabilities are held to be important for each and every person: each person is treated as an end, and none as a mere adjunct or means to the ends of others'. Indeed, Nussbaum applies capabilities in just this way to the individual Vasanti (e.g. 2011, ch.1) whose life experiences she interprets to 'make assessments of minimal social justice' (2011, p.20). As Davidson et al (2009, p.38) succinctly put it: 'The capabilities approach was initially developed by economic theorists and political philosophers keen to emphasize that any legitimate approach to social justice must begin with the recognition that human beings are agents who need to be free to determine their own lives'.

This sociological study is consistent with these accounts of capabilities and their implied or expressed accounts of liberal social justice. The concluding chapter returns to discuss the learning from the application of social justice to the experiences of individuals.

The concept of social justice is used in the study, in preference to, for example, wellbeing. The notion of wellbeing for people with mental distress is strongly contested, having been shaped by dominant social norms, notably through the contested historic role of the medical profession (see the sociological literature in Chapter two). This contestation continues, for example, in relation to contemporary Scottish mental health law (Section 1.4 below). This context makes wellbeing specifically problematic as both a term and a concept to evaluate capabilities-based outcomes for the participants in this study. Therefore social justice, following Nussbaum's interpretation above, is the stronger analytical basis for a capabilities interpretation of findings in this study. However, the relationship between agency and wellbeing is significant in the capabilities literature (Chapter three) and informs the evaluation of experiences of social justice, as seen in the data chapters below.

This study therefore reinterprets Venkatapuram's definition of health justice (2011, p.20), the 'abilities to be and do things that make up a minimally good, flourishing and non-humiliating life for a human being in the contemporary world' as a definition of social justice. This social conception allows this study of an ostensibly health-related topic to be evaluated as a question of social justice, asking: what social justice did participants experience - what were they actually able to be and do - and how can these outcomes be explained using a sociologically informed capabilities approach?

## **1.2 Terminology: 'mental distress' and 'people with mental distress'**

Due to the contested epistemologies of research in this field (Chapter two), empirical sociological literature exploring this social group needs to justify its terminology. There are two dimensions to this. First, why the term 'mental distress' is selected and what is meant by this term in the context of the sociological literature. Second, why 'people with mental distress' is selected as the collective noun, as opposed to other terms or phrases, and what this phrase encompasses.

Why use the term 'mental distress'? First, terms such as 'mental illness' or 'mental disorder' may denote or imply illness or incapacity (Beresford, 2002; Tew, 2011, p.5), which may be subjectively contested. Parr (2008, p.29) has justified using a variety of terms based on user-led, or 'survivor' literature, including the term 'mad'. Coles et al (2013, p.vii, n.1) have argued for the use of the term 'madness' to 'detach ourselves from the restriction of medicalised conceptualisations of experience and behaviour...' However, Beresford (2010, p.27), an academic and 'survivor' of the mental health system, has posited that:

Service users ... have tended to talk much more about 'distress' - emotional and mental distress - than mental health or mental health problems. Some also talk about madness although some others are uncomfortable with the term.

Alongside the term 'service user/survivor', 'mental distress' is one of the terms favoured by the survivor movement of users of psychiatric services (Beresford,

2002, p.582; Tew, 2011, p.5; Plumb, 2012, p.20), and it is for this reason that the term is used in this study.

The term 'people with mental distress' is therefore used throughout this study as a collective noun. However, this term still contains two dimensions, reflecting the critical thinking that has characterised the sociology of mental distress. The sociology of mental distress stems from critique of the coercive character of the psychiatric system, and the field has been responsible for a persistent critique of the disjuncture between subjective feelings of emotional distress and the psychiatrisation of people: use of the psychiatric system does not necessarily correlate with experience of subjective mental distress. This and many further critiques are explored in Chapter two. So, the term 'people with mental distress' encompasses both those who view themselves as having experienced subjective mental distress and have used the mental health system voluntarily or through coercion; and also those that may not view themselves as having experienced subjective mental distress and have used the mental health system. So, for the purposes of this study 'people with mental distress' is defined as being people that have personal experience of the mental health system, reflecting that this use of the system does not in itself evidence experience of subjective mental distress.

The distinction between internal feelings of subjective mental distress and the broader understanding of mental distress in terms of having experience of the mental health system becomes particularly important in the discussion on personal Conversion Factors in Chapter three, and then throughout the thesis.

A final note on terminology. Whilst the empirical sociological literature tends to contemplate the use of a collective noun for this social group as a whole, fewer studies have engaged with the question of how to write sociologically about medicalised diagnostic terms used to describe different types of subjective mental distress experience in a way that both reflects the empirical reality of the use of medicalised terms by research participants, and which demonstrates analytical awareness that these terms are contested. Beresford has argued that diagnostic categories such as 'schizophrenics', 'manic depressives' or 'bipolars' (2012, p.154) reduce people to an objectifying and demeaning set of symptoms, which the evidence suggests also lack accuracy and consistency (see Chapter

two). Pilgrim and Bentall (1999) deal with this by using, somewhat inconsistently, quotation marks to distinguish the social construction of 'depression' as a diagnosis. In contrast, Tew (2011, pp.29-34), in a social perspective work aimed at professionals, describes different types of subjective mental distress experiences by using a distinct lexicon, including terminology such as losing emotional balance, including depression; mood swings; a range of experiences collected under the term psychosis; disassociation; and hearing voices and other hallucinatory experiences.

This study follows Pilgrim and Bentall's (1999) critical realist paper by using quotation marks when the analysis requires use of diagnostic terms used by the psychiatric system (e.g. 'depression'). However, where participants subjectively use diagnostic terms without critique, the study reports these without the distancing of quotation marks, reflecting Beresford's point that for some people the medical model may be 'the only conceptual framework they have ever known' (2002, p.582).

### **1.3 Research problem and research questions**

The research problem that this study seeks to address is how the social justice experiences of people with mental distress can be more fully understood. The study explores this through analysis of the lived experiences of a sample of people living in Glasgow with recent in-patient experience of psychiatric hospital. It explores the utility of the capabilities approach as a normative means to interpret these experiences. The study has four specific aims:

1. To understand the relationship between personal, social and structural factors affecting the lived experiences of the sample;
2. To consider the character of social justice experienced by participants and to conceptualise this using concepts from the capabilities approach;
3. To take a critical realist approach to understanding how the social justice experiences of participants may be produced and reproduced;

4. To pursue these aims with regard to both values-based research principles from the survivor-influenced literature (Tew et al, 2006) and the participation principle from the capabilities approach (Nussbaum, 2006).

Theoretically, the study seeks to establish in what ways the capabilities approach is useful for understanding the social justice experiences of people with mental distress and so, to paraphrase Beresford (2010, p.57), for reconceptualising mental distress within a social framework. How does the study then critique the capabilities approach? What does critical realism add to the interpretation of findings?

Methodologically it seeks a research design that is sufficiently sensitive to explore differences in functionings and capabilities across a sample of people with mental distress. It requires methods that build on understandings gained from compatible paradigms of research exploring the lives of people with mental distress.

Substantively the study requires an approach that facilitates interpretative and normative conclusions. First, what this study tells us about the lives of people with mental distress in terms of social justice, including what personal, social or structural factors can be identified that impact on social justice for different people within that social group. Second, conclusions which indicate what should be done to overcome social injustices for members of this social group.

## **1.4 The law**

The study has sought to recruit people that have had experience of being in-patients at psychiatric hospital since the introduction of the Mental Health (Care and Treatment) (Scotland) Act 2003 (MHA 2003) in January 2006. Their admission may have been voluntary or may have been compulsory - colloquially known as being sectioned. For either group, the MHA 2003 is part of their context once admitted to psychiatric hospital. It is thus important at this stage to set out the formal aims and principles of this Act.

The MHA 2003, based on the review of the previous (1984) Mental Health Act, sought to reconfigure the terms of administration for psychiatric treatment. It

defined what it terms ‘mental disorder’ as ‘any mental illness, personality disorder or learning disability however caused or manifested’ (S.328), and introduced a set of ten core principles, including equality, participation, maximum benefit, least restrictive alternative and reciprocity. These were to be adhered to by persons discharging functions under the Act towards people with ‘mental disorders’, including psychiatrists and Mental Health Officers, the professionals with the power to determine that a person may have a ‘mental disorder’, so making them potentially subject to the Act.

Whilst short-term and emergency detention could be made by approved medical professionals, applications for longer-term detention, or Compulsory Treatment Orders (CTO), formerly determined by a sheriff, were in the MHA 2003 moved to a tribunal system involving legal, medical and lay members. For an individual to be subject to a CTO, five criteria of equal worth needed to be satisfied, in sum: evidence of a mental disorder; suitability for treatment; risk (to self or others), significant impaired decision making ability; and necessity. The MHA 2003 also introduced the Community-Based Compulsory Treatment Order, aiming to widen compulsory treatment for people with a ‘mental disorder’ outside the hospital setting. Individuals were entitled to legal representation at tribunals, and hospital management had a new duty to ensure that patients were made aware of their rights under the Act. Mental health service users had new rights for access to advocacy and the right to make advance statements stating their treatment preferences.

Rogers and Pilgrim, taking a critical realist perspective, have argued (2003, p.181) that in the mental health system power imbalances sustain coercion by mirroring ‘(usually implicitly) the normative concerns of the social order both parties inhabit’, so:

Voluntary and coercive control coexist in psychiatric practice at any particular time ... Thus, when any person presents themselves or is presented by others to psychiatric attention, they enter a social space in which an inequality of power operates.

The hegemonous biomedical understanding of mental distress critiqued by the sociology of mental distress is implicit in the underpinning dominant norms stemming from the Enlightenment and the social contract (Chapter two), as are

the theories of social justice critiqued by the capabilities approach (Chapter three). In the context of mental distress these dominant social norms have led to tendencies to classify people through modernity as being normal or abnormal, rational or irrational, healthy or unhealthy, expressed through the predominance of medicine (see Chapter two). As part of this process, the psychiatric system becomes socially understood as neutral and necessary, a form of governmentality (Foucault, 1991), whilst incorporating elements of oppression, regulation, confinement, surveillance and biodeterminism (Rogers and Pilgrim, 2003, pp.5-6). The social justice outcomes for people with mental distress from this arrangement have been empirically very poor (Chapter two).

So, in this context, some experiences of mental distress become constructed under law as ‘mental disorder’ bringing individuals thus categorised into the aegis of mental health laws and practices. These can be seen in the MHA 2003 as enabling medically trained professionals, where required with the consent of a panel including lay membership, to define the existence of a ‘mental disorder’ which is treatable, holds risk, which significantly impairs decision making ability, and which requires constraint of freedom to be treated. These five categories imply their binary opposites (not mentally disordered, free, untreatable, no risk, without significantly impaired decision-making ability). The MHA 2003 can thus be seen as reinforcing the tensions of modernity, as above, but specifically in this case sifting people into five implicit corollary categories of normal/abnormal (or sane/insane), free/bounded, presentable for medical treatment or not, safe/unsafe, and rational/irrational (or competent/incompetent). In this context, the rights and principles in the MHA 2003, which guide ‘how professionals should work when providing treatment and care under the Act’ (Mental Welfare Commission for Scotland, 2014),<sup>1</sup> such as equality, participation, maximum benefit, least restrictive alternative, reciprocity, advance statements and advocacy, are revealed as simply placing limits of human decency in terms of how medical professionals enact their powers to operationalise for individuals the boundaries of dominant social norms that place human behaviours on one side or other of these dualities. Those subject to the Act are then obliged to accept medical treatment, and so

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<sup>1</sup> At <http://www.mwcscot.org.uk/the-law/mental-health-act/principles-of-the-act/>, sourced 31 March 2015.

modernity's norms of confinement and medicalisation of people with mental distress are continued. The domination of the biomedical model of psychiatry in the interpretation of mental distress is further discussed in Chapter two and the impact of mental health law on participants is discussed in the data chapters, notably Chapters six and eight.

## **1.5 Structure of the thesis**

Chapter two evaluates purposively selected literature to identify the empirical, theoretical and methodological gaps in sociological analysis of mental distress with which this study engages. It sets out the dominant medical perspective against which the sociological literature sits and demonstrates the social injustices generally experienced by people with mental distress as described by macro-level literature. It divides the sociology of mental distress into four cross-cutting themes, concluding by noting the gaps posed by the existing literature and setting down the epistemological challenge made by critical realism.

Chapter three establishes the normative principles of the capabilities approach, and lays out the main tenets used by this framework in analysing social phenomena. It brings in sociological critique to demonstrate how the capabilities approach can be made more analytically robust.

Chapter four takes a reflexive stance to explain the strategic and methodological approach to the study. It evaluates how the capabilities approach has been applied to studying people with mental distress and other groups experiencing social injustice. The chapter builds on this knowledge to set out the qualitative research design for the study, describe the sample recruited, and reflect on the research process.

Chapters five, six and seven interpret the empirical data to illuminate how living with mental distress, living with the mental health system, and living in society respectively influence social justice outcomes for participants. Chapter five relates participants' descriptions of their subjective experience of mental distress, their understanding of its causes and how the experience felt to them, including suicidal feelings, and how these experiences relate to their social justice. Chapter six then explores the impact of elements of the mental health



system on participants' subjective mental distress and on their social justice. Chapter seven interprets ways in which participants used their agency whilst living in society with mental distress, and describes how family and intimate relations and prejudice and discrimination influenced social justice for participants. It finishes with an analysis of participants' experiences of education, employment and income, socially valued domains of life in which people with mental distress tend to experience social injustice.

The first three data chapters analyse the social justice experiences of participants in an open, exploratory manner reminiscent of the approach of Amartya Sen. Chapter eight then uses Martha Nussbaum's most distinctive contribution to capabilities, a list of central human capabilities ('domains'), as a means to further interpret participants' experiences of social justice. It explores whether domains emerging from consultation with other groups typically experiencing social injustice 'speak' to people with mental distress, and offers the sample a means to critique, amend or expand these. The Chapter also interprets the data to contribute to some conceptual and theoretical questions for the capabilities approach from the perspective of the participants in this study.

Chapter nine, discussion and conclusion, draws together some original substantive, methodological and theoretical contributions from the study. Drawing on the critical realist approach that has underpinned the study, it outlines a nascent critical capabilities model of mental distress, before noting study limitations and future directions.

The study discovers that participants have characteristics of surviving, thriving and being outside. These are referred to through the data chapters so are important to describe at this stage. They are expanded on in the discussion and conclusion chapter. To explain these using a combination of sociology and capabilities concepts: first, having characteristics of surviving means living within dominant social norms but experiencing capability deprivation (see Chapter three), and so experiencing social injustice. Having thriving characteristics means also living within dominant social norms but having a wide capability set (see Chapter three) and therefore experiencing social justice. Having characteristics of 'being outside' means challenging a dominant social

norm as part of a capability set, resulting in potential difficulties in ability to 'convert' some capabilities and achieve social justice due to that very challenging. These form a typology, or overall classification, and the same individuals may be in all three characteristic groups at different times, or at the same time but in different domains of life. However, the bulk of the data reveals that participants had characteristics of surviving, with smaller experiences of thriving and being outside. This spread reinforces what is suggested in the macro-level data about the social injustices experienced by the mass of people with mental distress. However, this qualitative study nuances assumptions of social injustice by illuminating, using sociological and capabilities concepts, how differential social justice outcomes tend to happen.

## **2 Understanding lived experiences of mental distress**

### **2.1 Introduction**

There is a missing link between sociology and the capabilities approach, which, if bridged, could provide analytically fruitful for both schools (Holmwood, 2013). One aspect of the originality of this study is bringing together the capabilities approach with sociology in the context of mental distress. The purpose of the next two chapters is therefore to conduct an applied and critical review of these two literatures, resulting in a synthesis which adds sociological substance to the capabilities approach and applies to sociology an original means of interpreting the lives of people with mental distress.

The literature evaluated in this chapter is purposively selected to identify the empirical, theoretical and methodological gaps in sociological analysis of mental distress with which this study engages, and so is not representative of the literature as a whole. The boundaries of the literature selected inform the underpinning ontological and epistemological assumptions of the study, define the scope and salience of the research topic (the research 'gap'), and identify the relevance of the concepts applied. Rogers and Pilgrim emphasise that there are no set boundaries to sociological research in mental distress and that perspectives cross-cut, producing 'sedimented layers of knowledge' (2010, p.11). The review includes authors that have been seminal in the field and papers that influenced the original proposal for this study, notably from the sociology of mental health influenced by disability studies (e.g. Plumb, 1994; Beresford, 2004). The data produced through the study have led to my critiquing these studies in a way that was not possible when I started the research.

The sociological review is necessarily contextualised. First, by critical description of the dominant medical framing of the experiences of people with mental distress against which most of the sociology rests, and which continues to play a dominant role in lived experience. Second, by the macro-level literature which indicates the social injustices still experienced by this social group after generations of the dominant medical model. The sociology is then explored through the following cross-cutting themes. First, structural functionalist and

historical-critical reviews of the dominant medical model of explanation, notably Parsons and Foucault. Second, symbolic interactionist and social constructivist-influenced studies, explaining the social implications of the medical model in terms of diagnosis, stigma, labeling and deviance in particular, notably Szasz, Scheff and Goffman. Third, theoretical and empirical studies influenced by the mental health user or survivor movement, demonstrating the ongoing social injustice experienced by people with mental distress in the context of the predominant biomedical model, notably Beresford, Plumb, Tew, Barham and Hayward, and Parr. Fourth, the recent critical realist 'turn' which aims to overcome the analytical reductionism of earlier sociologies of mental distress (Bentall, Rogers and Pilgrim, and Scambler). The chapter concludes by specifying the research gap left by these studies and addressed in this study, namely to better incorporate agency and normativity into a least reductive understanding of social justice for people with mental distress, and proposing that the capabilities approach, analysed in the next chapter, is compatible with the sociology of mental distress and consistent with challenge made by critical realism.

## **2.2 The dominant medical perspective on mental distress**

The dominant model of interpretation of certain emotional experiences as 'mental illness' and the contingent model of treatment as being through a part-coercive psychiatric system of asylums, hospitals, diagnoses and physical, chemical and psychological interventions was based on a number of dominant post-Enlightenment influences. These included notions of rationality and irrationality (Foucault, 1967; 2009) the power of the medical profession (Scull, 1975; Foucault, 1967, 2009; Porter, 1987, ch.2), and the impact of the 1834 Poor Law in which to merit support people were categorised by the state across five categories including the sick, the insane and 'defectives' (Oliver and Barnes, 2012, p.64), with the medical profession gaining powers in diagnosis, exclusion and surveillance. Foucault has argued (1967; 2009) that these processes, alongside the rise of asylums, both confined undesirable humans and led to a medicalised understanding of 'madness' as both an ahistorical, natural object for study and an illness to be cured. This led to dominant binary norms of 'rational' and 'irrational' behaviours, especially in regard to those at risk of being classified as 'insane'. For Porter (1987, p.24) mass incarceration

‘...became a self-fulfilling prophecy, by forcing those labelled as abnormal to live under circumstances precluding normal living’. The predominant power of the state and psychiatric professionals in classifying people as ‘sane’ or ‘insane’ continues today in more subtle forms incorporating community care and notions of ‘recovery’ (Anthony, 1993), which may be more powerful and insidious (Davidson, 2003, p.36).

The dominant medical model was not the result of conspiracy or will to harm, but was formed in the context of a political and moral order (Foucault, 2009, pp.128-129) and followed the epistemologies of medical intervention for physical illness (Scull, 1975), based on diagnosis, prognosis, aetiology (cause), and chemical or physical treatment, perhaps followed by psychological treatment (Rogers and Pilgrim, 2010, pp.2-3,155), all with the underpinning assumption ‘that there is some underlying pathological process’ (Busfield, 2011, pp.17-18) explaining the expression of mental distress.

By the late 1970s within psychiatry the social dimensions of experiences of mental distress had become more strongly acknowledged. However, for Tew (2011, p.25) the biopsychosocial model (Engel, 1980), ostensibly recognising non-organic dimensions of explanation of mental distress, continued to presume:

...that social or psychological factors played only a subsidiary role in triggering underlying mental ‘illness’ - and, by implication, had a similarly subsidiary role as an adjunct to medical interventions in its treatment.

For Rogers and Pilgrim the ‘stress-vulnerability’ model was then similarly captured by ‘bioreductionism’ (2003, p.231). The Diagnostic and Statistical Manual (DSM) and International Classification of Disease (ICD) have continued to be revised, with the number of diagnoses multiplying, and a new generation of trenchant and impactful internal critiques emerging.

In response to this ‘biological turn’ (Busfield, 2011, p.121; Szasz, 2011), a ‘post-psychiatry’ response has internally critiqued the ‘diagnosis and medication first’ model and the dominant biomedical paradigm of psychiatry, whilst reinforcing that medication or ‘technical interventions’ (Bracken et al, 2012, p.430) remain the primary building block of treatment for mental distress. In the psychiatry of

the late 20th C. (Double, 2002, p.903; Bentall, 2003, p.44; Rogers and Pilgrim, 2003, p.169) relational analyses have maintained a secondary position to the biomedical approach, in which diagnosis, hospitalisation, coercion, and drug-based 'treatment' have dominated psychiatric understandings of, and therefore the implications of experiencing, mental distress.

Generations of this medicalised process through the 20<sup>th</sup> C. have provided some benefits for people with mental distress, evidence suggesting that medication, for example for psychotic feelings can reduce distress at least in the short-term (Bentall, 2009, pp.219-221) and reduce repeated experiences in the longer term (Bentall, 2003, p.499); that diagnosis can provide subjectively helpful explanations for confusing emotional experiences (e.g. Stalker et al, 2005); and people with mental distress now spend less time living in physically segregated institutions (Bentall, 2009, pp.42-44; Busfield, 2011, p.178).

However, as will be seen throughout this chapter, the dominant medical model has been subject to extensive sociological critique (e.g. Rogers and Pilgrim, 2003, ch.8; Bentall, 2009). It is important to raise some of the most *prima facie* concerns here. In sum, Pilgrim and Tomasini (2012, p.633) have noted that psychiatric diagnoses have:

...poor conceptual validity (two patients with the same label may have little in common), poor predictive validity (future outcomes or prognosis are not clear for particular patients), poor aetiological specificity (we do not know the cause of the problem), poor understanding of pathogenesis (we do not understand the mechanisms leading to particular symptoms) and poor treatment specificity (common treatments are used across diagnostic boundaries).

Moncrieff (2008) has used Foucault to highlight the dominance of psychiatric power in shaping both the construction of classifications of schizophrenia, bipolar disorder, depression and anxiety and the concomitant construction of drug treatments, the 'disease model' (2008, p.5) being compatible with drug-centred treatments also promoted by the interests of the pharmaceutical industry.

Psychiatric medicines more generally have a multiplicity of deeply unpleasant, unpredictable and sometimes dangerous iatrogenic effects, including both older

and newer generations of antipsychotic (e.g. Moncrieff, Cohen and Mason, 2013; Bentall, 2003, pp.499-503; 2009, pp.208-212). Post- psychiatry has reiterated these concerns including for ‘new generation’ antidepressants including selective serotonin reuptake inhibitors (SSRIs) (e.g. Tyrer and Kendall, 2009; Bracken et al, 2012).

The evidence strongly indicates that social justice outcomes for people with mental distress continue to be poor (see next section), reinforcing the limited gains of the medical model of interpretation and treatment. For Rogers and Pilgrim (2003, Introduction), this is due to distinctions between mental and physical health in terms of subjective experience, social determinants, medical treatments, social meanings and political responses. It is also influenced by the dominant discourses stemming from post-Enlightenment values which have marginalised those experiencing mental distress (Foucault, 1967; 2009). The experience, understanding and treatment of mental distress cannot in sociology be removed from the structural and social context. So, Fisher has highlighted the almost doubling of reported mental distress under late capitalism (2009, pp.35-38), arguing that neo-liberalism forecloses political explanation of systemic causation by pathologising mental distress as individual chemical imbalance, resulting in an ideological avoidance of explanation with reference to the underlying structure (see also James, 2008). These wider explanations require sociological exploration in the current context.

The ‘chemical imbalance’ model (Moncrieff, Cohen and Mason 2013, p.213; Moncrieff, 2008, pp.9-11) or ‘no fault’ brain disease model (Sayce, 2000, p.99) of ‘mental illness’ continues to dominate medical research and treatment with implications for how people with mental distress are viewed by society as responsible citizens or otherwise; how people with mental distress view themselves and their possibilities; and how models of treatment become skewed towards pharmaceuticals (Sayce, 2000, ch.4; Moncreiff, 2008).

Mary Boyle warns: ‘It is easy to underestimate the sheer adaptability of the medical model and its power to shift our attention, to invalidate, assimilate and neutralize challenges’ (2013, p.20). As an example, the concept of recovery has become a dominant discursive feature in UK mental health policies (e.g. Scottish Recovery Network, 2006). Stemming from the survivor movement (Perkins and

Repper, 1998, pp.18-19), focusing on ‘challenging existing notions of mental health and proposing alternative notions of emotional distress’ (Harper and Speed, 2012, p.15), it has been co-opted through the combination of the resurgent biomedical model with neoliberalism, tending to promote individualistic recovery strategies, raising ‘serious questions about the social justice implications’ (Howell and Voronka, 2012, p.2) of recovery, whilst ‘reinstating the expertise and authority of psychiatry and psychology’ (Howell and Voronka, 2012, p.4). This assimilated model of recovery has failed to incorporate ‘the dominance of psychiatric pathology or economic inequalities and the impact these factors have in perpetuating emotional distress’ (Harper and Speed, 2012, p. 18), or place sufficient emphasis on the diversity of means to achieve ‘recovery’ (Davidson, 2003; Harper and Speed, 2012, p.19), so diminishing agency (Chamberlin, 1998).

Rogers and Pilgrim in their critical realist account of lived experience of mental distress highlight the importance of power over knowledge claims in this context. They highlight the normative function of this power in terms of social control of psychiatric knowledge, the professional interests in maintaining its dominance, and the individualisation and reductionism of analysis that follows, mirroring the findings of this section. They argue that lay knowledge based on lived experience ‘provides a closer fit with the social conditions and personal experiences which give rise to mental health problems’ (2003, p.189). However, it is against the dominant, medicalised model of understanding and treatment, alongside the evidence of people with mental distress experiencing macro-level social injustices, which the sociology of mental distress has been positioned through the past century.

## **2.3 Macro-scale data on social justice experiences of people with mental distress**

Over a century of the medical model, the multiple changes in diagnostic classifications, generations of treatments, reframed laws affecting people with mental distress, and the change from asylums to community care and from care and support to recovery as the dominant medical approaches have, however, had little impact on social justice experienced by people with mental distress (Marmot, 2010; Allen et al, 2014). As the WHO have noted (2009, p.1):



...mental illness, across the spectrum of disorders, is both a direct cause of mortality and morbidity and a significant risk factor for poorer economic, health and social outcomes, although these adverse outcomes vary by type of disorder and socioeconomic status...

A brief, critical review of macro-scale data helps to explain why this study is important in terms of social injustices experienced by people with mental distress as a group.

Epidemiological studies are subject to sociological critique in particular for their lack of critique of 'pre-empirical conceptual problems associated with psychiatric knowledge' (Rogers and Pilgrim, 2010, p.12). The application of psychiatric categories in these types of study reinforces the power of their knowledge claims as being objective rather than socially constructed (Rogers and Pilgrim, 2003, pp.36-40), so underpinning the dominant, medicalised model of understanding and treatment (e.g. WHO and Calouste Gulbenkian Foundation, 2014). Nevertheless as people categorised with 'mental illness', 'mental disorder' or any of the many diagnoses within these are not allocated randomly across populations (Marmot, 2010, p.54), it is reasonable to judge that data collected on the basis of these categories do have some positive correlation with subjective feelings of emotional distress and so do provide an indication of social justice outcomes for populations with mental distress.

For Busfield (2001) epidemiological studies (e.g. Faris and Dunham (1965[1939])); Hollingshead and Redlich (1958); Brown and Harris (1978), cit. Busfield, 2001, pp.6-9) have demonstrated that social factors must be brought into the understanding of the causation of mental distress for individuals, bringing a dimension of relativism back into psychiatric categorisation. She argues (2001, p.9) that they have provided a rejoinder to genetic explanations of mental distress, for example Brown and Harris (1978) finding that social processes were implicated in the origins of both endogenous and reactive depression. For Tew, epidemiological studies have explored the relationship between social disadvantage and mental distress and have demonstrated correlations with poverty and other social determinants (2011, chapter three). These types of study have therefore been able to critique the biomedical model and have provided evidence that has informed the social determinants of mental distress

and the need for ‘upstream’ actions to address social justice, now advocated by authorities such as Marmot (2010) and Wilkinson and Pickett (2009).

Macro-level data has contributed to understanding social determinants of mental distress in a number of ways. The WHO and Calouste Gulbenkian Foundation linked income and relative poverty, unemployment and poor quality employment with risk of mental disorders (2014, p.24). The World Health Organization Commission on Social Determinants of Health (2008), including Amartya Sen and chaired by Marmot, argued that ‘Social injustice is killing people on a grand scale’ (2008, p.26), even more so for people with mental distress (2008, p.98, Table 9.1) determined by socioeconomic context and position, exposure, vulnerability and health care access. Thornicroft (2011, p.441) saw that:

The fact that life expectancy remains about 20 years less for men with mental illness, and 15 years less for women with mental illness ... shows, in stark terms, by just how much people with mental illness are categorically valued less than others in our society.

Macro-level data strongly suggest that people with mental distress are not a minor social group. The WHO and Calouste Gulbenkian Foundation report (2014, p.23) notes that ‘In England, one in four people experience a mental disorder during their lifetime and 17.6% of adults experience at least one common mental disorder’. The Scottish Government (2012) cites data that whilst about 1-2% of the European population experience ‘psychotic disorders’, ‘mental disorders’ affect about one-third of the population annually, with ‘depression’ being ‘the leading chronic condition in Europe’ (2012, p.4). Within this larger social group of people with ‘mental disorders’, this study has a focus on the small minority who have also had experience of psychiatric hospital. The participants in this study are therefore likely to be particularly vulnerable to the social injustices described below affecting the group as a whole.

In terms of the basic social justice outcome of an equal lifespan, people with ‘mental disorders’ in Scotland die on average more than ten years earlier than the general population, a gap which is widening (Scottish Government, 2012, p.5). The gender distinction made by Thornicroft, above, demonstrates the relativity of classification.

In terms of the normative concern of both sociology and the capabilities approach with equality (e.g. Sayer, 2009; Sen, 1992, Introduction), Marmot (2010, p.54) notes that in England the social gradient is particularly pronounced for 'severe mental illness', the prevalence of 'psychotic disorders' amongst the lowest quintile of household income being nine times greater than in the highest. In the context of the current study, Shipton and Whyte (2011) note that between the most and least deprived population quintiles living in Greater Glasgow and Clyde there were over twenty-fold differences in hospital discharges with diagnoses of schizophrenia and neurotic disorders, and ten-fold for mood disorders. Greater Glasgow and Clyde has the highest number of community-based and hospital Compulsory Treatment Orders per 100,000 people in Scotland including emergency and short-term detentions (Mental Welfare Commission for Scotland, 2012, p.27). Mental distress is also gendered: males in Greater Glasgow and Clyde were almost twice as likely as females to be discharged from hospital with a diagnosis of schizophrenia (Shipton and Whyte, 2011); women were 50% as likely as men to have a mood-related psychiatric discharge (Shipton and Whyte, 2011).

In terms of wider social justice outcomes, in the UK social surveys consistently suggest that people diagnosed with medicalised categories of mental distress are more likely than most people to live in relative poverty (Rethink, 2003), be victims of violence (Office of the Deputy Prime Minister (ODPM), 2004, p.25), live in disadvantaged areas (Tew, 2011, p.37), live on their own (ODPM, 2004, p.86; Mind, 2004), to have financial problems such as rent arrears and debt (ODPM, 2004, p.85), and to have less access to justice (ODPM, 2004, p. 91; EHRC, 2011), to transport (ODPM, 2004, p.92), and to employment (ODPM, 2004, p.1). They also tend to experience stigma and discrimination due to prejudice (ODPM, 2004, p.24). People with mental distress also tend to experience disproportionate discrimination at work (e.g. Coppock and Dunn, 2010, pp.111-112). Large-scale studies suggest that people with mental distress in the U.K have poor quality of life indicators in terms of health, employment, income, housing and family life (Wilkinson and Pickett, 2009; Scottish Executive, 2004; WHO, 2004, 2010). People with 'mental disorders' account for 43% of social welfare benefits claimed in Scotland (Scottish Government, 2012, p.4).

The evidence for people with mental distress living in the community being more dangerous to other people than any other citizen is weak (ODPM, 2004, p.25) and remains a problem of public perception (ODPM, 2004, p.26). Despite this, people with mental distress are hugely overrepresented in the prisons system (e.g. Bradley Report, 2009, pp.8-9).

Suicide and self-harm emerge as an issue in the data chapters. Whilst suicide is a low probability act, and far from confined to those with a diagnosis of mental distress, psychiatric populations are more prone to suicide than the general population, over tenfold so for people with diagnoses of 'schizophrenia' or 'a major affective disorder' (Rogers and Pilgrim, 2003, p.162). Dowrick (2009b) notes meta-analysis evidence which suggests the risk of suicide increases by twenty times for those with a diagnosis of major depression, and about fifteen times for those diagnosed with bipolar disorders. So although there has been a 19% fall in suicide rate in Scotland between 2000-2002 and 2011-2013<sup>2</sup> the relationship of this to incidence of experiences of mental distress is tentative.

Epidemiological data risk underpinning medical power over knowledge claims, and so reinforcing dominant norms of understanding mental distress through which have been shown to be invalid and unreliable categories. Macro-level data also risk stereotyping people with mental distress as experiencing poor social justice. However, these data do provide persistent indicators of social injustice experienced by people with mental distress, demonstrating the normative gap explored in this study, with Busfield (2001) also arguing that epidemiological studies are not necessarily incompatible with critical thinking about disorder over time and place, an implicit fit with critical realism.

## 2.4 Functionalist and historical-critical reviews

This section explores how structuralist sociologies have explained the social position of people with mental distress using functionalist theory (Parsons) or based on conflict theory (Foucault).

In the early- and mid-20th Century, social scientific thinking tended to compatibility with the dominant biomedical model of understanding and the

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<sup>2</sup> [www.chooselife.net/Evidence/statisticssuicideinscotland.aspx](http://www.chooselife.net/Evidence/statisticssuicideinscotland.aspx), sourced 19 March 2015.

associated psychiatric system as a model of treatment (Rogers and Pilgrim, 2003, pp.36-38). Influenced by Durkheim's analysis of rules of acceptable social conduct (cf. *The Rules of Sociological Method*, 1895) the grand theory of Parsons (1951) explained the functional role of sickness in contributing to social stability. The 'sick role' (1951, pp.428-479; Busfield, 2001, pp.3, 10) identified two implied social rights for sick people, the exemption from normal social roles and from responsibility for their own state, alongside two obligations: to want to get well quickly and to consult expert medical opinion. The sick role for Parsons, further 'channels deviance so that the two most dangerous potentialities, namely, group formation and successful establishment of the claim to legitimacy, are avoided' (1951, p.477) thus stopping the sick 'forming a solidary collectivity' (1951, p.477). This was one explanation of how the social system maintained its stability. By implying a lack of conflict and placing the responsibility on the individual to get better, the sick role could be interpreted as the precursor to the contemporary recovery model.<sup>3</sup>

So Parsons' analysis took a structural functionalist approach, neglecting the potential for agency and social conflict. His individualising of the patient and the benign role he suggested for the medical profession were subsequently challenged, including through emergent symbolic interactionist ontology and by the genealogical analysis of Foucault.

Cladis (1999, p.11) observed that Foucault converged with Durkheim in terms of sociological method, taking an almost anthropological approach to compiling evidence to uncover social structures, practices and norms; analysing these findings without a priori or circular assumptions, focusing on 'the social construction of knowledge, power and the subject' (1999, p.10). Foucault (1967; 2009) used a socio-historical approach to demonstrate that the rise of psychiatry was a socially constructed moral project. He argued that large scale confinement of the 'mad' in Europe started in the 17th C., beginning the age of madness defined as a social problem, associated with incapacity to work and social separation (1967, p.64). This led to the rise of the asylum system, and tension between suppression and correction of madness (1967, pp.115-116, 184). Foucault underpinned his argument with a focus on the emergence of 'scientific

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<sup>3</sup> Thanks to Nick Watson for this argument.

psychiatry' (1967, p.158) holding increasing power of 'reason' on behalf of the state to categorise some as mad (1967, pp.250-255). Scull's (1975) comparable analysis explained the specific ways in which physicians gained power over those in asylums through use of medical argument pursued through political channels, empirically reinforcing Foucault's claims. Foucault identified a social class dimension to these social processes linking madness to disorder, negligence, debauchery and dissent, resulting in the state using 'madness' to sustain a particular moral order or dominant social norm (1967, pp.258-259).

Foucault brought a distinct historical and structural explanation of how power is reproduced through this process, explaining how the biomedical model became dominant. Foucault's argument is a social order critique of modernity, made in a comparable way to which Nussbaum (2006) explores dominant and unjust Enlightenment norms in relation to disabled people in a capabilities context (chapter three).

For Cladis, Foucault also took normative positions (1999, p.11), countering the critique that Foucault is persistently relativist (e.g. Sayer, 2012, p.781); for example Foucault (1967, p.277) suggested that mental illness could exist as a sometimes painful reality. For Bolton, Foucault's analysis (2008, pp.83-91), following the 'social-systemic gaze' (2008, p.90), diminished individual lived experiences. Foucault minimised the agency of the 'mad' in his analysis, the personal 'collapsing into the social' (Archer, 1995, in Williams 1999, p.812), with potentially mediating dimensions of difference (e.g. gender) and identity, including personal experiences of madness or unreason, left aside. Foucault in his later work (1982) acknowledged that he had underestimated the position of the self in social analysis at the expense of an analysis of domination and power.

Foucault's analysis enables the reader to see how definitions constructed by and through the state and state actors facilitate dominant discourses, leading to society tending to interpret certain emotional experiences as being individualised symptoms of an illness requiring medical treatment, this process resulting in exclusion from the dominant moral order. Ontologically, Foucault allows the world to be seen as bounded in multiple layers; epistemologically, after Foucault, within sociology a critical, 'denaturalizing' (Sayer, 2009) approach must be taken to concepts such as 'mental illness'; and

methodologically, empirical data must be situated. The power of psychiatry and the duality between suppression and treatment explored by Foucault continues to be prominent in the sociology of mental distress (e.g. Bentall, 2009, Ch.11) as seen later in the chapter.

So Foucault and Parsons focused on structure, diminishing agency. Whilst both implied the potential threat to the established order of people diagnosed with mental illness, Foucault's conflict theory-based explanation added a further layer of sociological critique. However, the inattention of structuralist studies to the agency of people with mental distress, or an explanation of how oppression did or did not happen for individuals with mental distress was addressed by another 'sedimented layer' of sociology (Rogers and Pilgrim, 2010, p.11), expressed through symbolic interactionist-influenced and social constructivist studies.

## **2.5 Symbolic interactionism and social constructivism**

The liminal, anomalous and ambiguous status of mental distress as a social category (Rogers and Pilgrim, 2003, pp.5-6) made it a prime site for the application of symbolic interactionist critiques of structural functionalist understandings of the social role of illness, fixed categories, consensual definitions (Blaxter, 2010, pp. 19-22), and its benign analysis of the role of the medical profession, and in response to the increasingly emergent weak validity and reliability of formal psychiatric diagnoses (Lemert, 1962, p.5). The connection made by Parsons between sickness and deviance also informed a series of symbolic interactionist-informed studies in the field of mental distress (e.g. Goffman, 1961, 1990; Lemert, 1962), from which theories of stigma, labeling and deviance emerged.

In *Asylums* (1961), Goffman empirically explored contemporary asylum practices, and identified multiple aspects of agency, if considerably structured, held by patients. Integrating a symbolic interactionist approach with social anthropology (Ritzer and Goodman, 2003, p.357) allowed Goffman to demonstrate how the social character of the institution generated the 'patient', leading them to behave in certain patterned ways, reinforcing both their status and that of staff. Whilst continuing to understand their social role as 'forcing houses for changing

persons' (1961, p.12) and 'total institutions' (1961, pp.1-124), on the face of it Foucauldian positions, the symbolic interactionist methodology of Goffman was not based on oppression; Goffman does not reveal the terrors of confinement made vivid by Foucault (1967; 2009).

Written in 1963, and like Parsons influenced by Durkheim's counterposition of normal and abnormal behaviours existing in all societies, in *Stigma* (1990), Goffman analysed the social processes by which stigma takes place. He constructed the argument that 'the ex-mental patient', amongst other groups, is viewed as having 'undesired differentness' from 'normals' (1990, p.15). His use of symbolic interactionist theory to expose the potentially devastating consequences of receiving a label or crossing 'the boundary between disorder and normality' (Busfield, 2011, p.129) revealed, as with Foucault, the social power of the psychiatrist in this context. However, Scambler subsequently developed Goffman's work (2006, p.290) arguing that structural determinants of social encounters and a theory of oppression require inclusion to explain causes and outcomes. Scambler's critique is developed further in the section on critical realism.

Social constructivism (Rogers and Pilgrim, 2010, pp.15-16) again assumed that reality is a product of human activity, so the lived experience of people, and how reality is constructed became the empirical focus. Rogers and Pilgrim make a distinction within social constructivism, that the less strong version argues that it is not reality that is socially constructed but 'theories of reality' (2010, p.16), making social constructivism of this type again compatible with critical realism.

Using a wide range of empirical examples from both psychiatry and the public, Scheff (1966) developed a sociological theory of how unusual behaviour can become interpreted as a manifestation of 'mental illness'. Critiqued by Thoits (1985, pp.221-222) leaving those with voluntary admissions or short-term experiences outside his analysis, Scheff developed the concept of 'residual' deviance (1966, pp.31-37), meaning the breaking of unstated social norms, to which people experiencing mental distress may be particularly liable (Busfield, 2001, p.3). Once labelled that way Scheff's theory suggested that a person, especially if they hold little social power, were apt to 'enter into the career of a mentally ill person' (Busfield, 2011, p.114). Again, the implication of this



analysis for understanding social justice outcomes requires the integration of structural explanation to understand how these dominant norms arise.

Scheff's account, as with Goffman, emphasised that a behavioural transgression needed to be socially perceived in order for a label to be applied. As seen in the macro-level data above, people do not receive labels randomly, but Scheff offered a critique of the validity of the category of 'mental illness' accepted by early epidemiology.

Szasz (1960), again pursuing analysis from a social constructivist perspective, also viewed mental distress as the breaking of dominant social, political and ethical norms, similarly to Foucault, Parsons, Scheff and Goffman (Busfield, 2001, p.3). For example, diagnosis for Szasz involved 'a covert comparison or matching of the patient's ideas, concepts, or beliefs with those of the observer and the society in which they live' (1960, p.114), making it inextricable from the social and therefore ethical context, highlighting that psychiatric diagnosis masks a moral judgment.

For Szasz 'What we do have are *problems in living* - whether these be biologic, economic, political, or sociopsychological' (1960, p.118, Szasz' emphasis). So whilst Szasz famously argued that 'mental illness' was a 'myth' (1960, p.113), ethically he held that people do suffer: 'life for most people is a continuous struggle, not for biological survival, but for 'a "place in the sun," "peace of mind," or some other human value' (1960, p.118), taking a normative position consistent with the concern of the capabilities approach for those experiencing social injustice.

Busfield (2011, pp.115-116) notes the commonalities between Szasz and Scheff. Each rejected the view that mental illness could be reduced to physical cause; supported the idea that the boundaries of 'non-organic mental illness' (Busfield, 2011, p.115) are determined by social norms and values; argued that actions considered 'symptomatic of mental disorder' (Busfield, 2011, p.115) should be understood in a social context; and agreed that medical control of mental distress was problematic. All these notions were taken up by survivor-influenced studies as seen in the next section.

Sedgwick concluded that these strands of sociology demonstrated ‘convincingly’ (1982, p.25) that diagnoses and treatments were founded on usually unstated ethical judgments, that ‘mental illness’ was a social construction and that psychiatry as a social institution reflected the values of the society in which it is located. However, methodologically, studies from the symbolic interactionist tradition have been shown here to reduce analysis to the individual to the neglect of a theory of oppression linked to structure. Social constructivist studies have revealed through Scheff the transgression of dominant social norms implied in receiving a psychiatric label, and through Szasz the power behind the medical label, reinforcing the work of Foucault.

## **2.6 Survivor-influenced social perspectives**

One of the methodological gaps in the above generations of studies was the marginalisation of the voices of people who had personal experience of using the psychiatric system. User perspectives emerged distinctively at a time in which other identity-based liberation movements, for example in disability, were also developing (Beresford, 2012; Menzies, Le Francois and Reaume, 2013), acting as a ‘countervailing force to experts’ control and production of knowledge’ (Rogers and Pilgrim, 2003, p.186). Survivor-influenced social perspectives took participation in studies by people with mental distress away from being the objects of medicalised or sociological research, to that of devising and leading research studies from a different epistemological starting point (Rogers and Pilgrim, 2010, ch.11).

Parr and Davidson have associated the mental health user movement with the reclamation of identity, from mental patients to ‘survivors’, ‘users’, ‘people with mental health problems’, and the reclaimed ‘mad’ (2009, pp.266-267), noting that user/survivor identity continues to be emergent, with tensions (2009, p.267). Plumb (1993, p.170) saw the survivor movement as constituting people with mental distress that are survivors of the psychiatric system, of social structures and institutions, and of cultural practices and values. This definition has regard to the dominant social norms which Foucault’s analysis highlights as shaping the psychiatric system. Yet, as Parr and Davidson (2009) argue, who constitutes ‘survivors’ remains ambiguous. The term risks becoming a label

placed by the 'survivor movement' on anyone that has used the mental health system, in the process removing agency.

Survivor accounts do incorporate the subjective reality of mental distress for some, and even subjective benefits of medication or elements of the psychiatric system (e.g. Beresford, 2005, p.43-45; Chamberlin, 1978; Read and Reynolds, 1996), framed within critique of the psychiatric system more generally. However, despite, as Beresford et al state, 'most service users [having] internalised' the medical model (2010, p.30), survivor-influenced research can lack evidence and analysis of the experiences of people that have no critique at all to make of the system (e.g. Reynolds et al, 2009).

For Menzies, Le Francois and Reaume (2013) the overarching term 'mad studies' forms a normative sociology of knowledge including survivor experiences, challenging both the dominant medical model and the narrow dominant conception of 'normality', in order to replace these with a system that provides better support for people and a more encompassing society embracing behaviours labelled by dominant discourses as 'mental illness'. Survivor-influenced studies therefore take an approach which does not simply accept the existence of current epistemologies as being the limit of what can save lives and improve social justice, but engage with the harder task of trying to create the academic base from which a new paradigm may emerge, as also seen in the paradigm shifts attempted by Foucault, Szasz and Sen, above.

Beresford, a self-identified survivor and academic who has discussed the problematic and beneficial aspects of his own distress and his experience of the psychiatric system (e.g. 2010, pp.8-12), has argued that social perspectives of mental distress must both highlight 'improved understanding of the *social origins* of impairment and impairment as a *social construction*' (2000, p.170, his emphases). Further (2002, pp.582-583), social perspectives need to 'challenge the underpinning conceptual framework ... based on the idea of 'mental illness'' and the negative values with which it is associated, so questioning the dominant ideology. Thus Beresford argues for an approach that is both, in Rogers and Pilgrim's (2010) terms, social causation, and socially constructivist, consistent with Szasz and Foucault.

For Tew (2011, p.27) the service user movement has 'been most influential in driving current debates' about the nature and meaning of mental distress. For example Beresford and Wallcraft have argued (1997, p.78) that survivor-led research challenges the medical paradigm through, for example, avoiding medical concepts and language as damaging and stigmatising; using the concept of 'crisis' or distress rather than 'mental illness'; interpreting hearing voices or other devalued perceptions and experiences as phenomena with a number of possible explanations, rather than as symptoms of 'psychotic illness' (e.g. Romme and Escher, 1993); and psychiatric treatments may be interpreted as abuse or torture, rather than medical treatment (1997, p.79). Beresford and Wallcraft have underscored the importance of survivor-led research to the development of principles for 'a clearer philosophical basis for the movement' (1997, p.82), highlighting: the social causes of mental distress; the medicalisation of distress experiences; discriminatory responses from both psychiatry and wider society; the need for a social response to distress, addressing the social origins and relations of distress; and the need for survivor-led alternatives to prevent distress and offer appropriate support. However, empirical studies engaging these concepts are limited.

For example, Beresford has most fully pursued the analysis of the principles and practice of the survivor movement and survivor research in the UK. However, across his work, Beresford's methodology tends to assertion and claim, with his empirical work being opaque in terms of evidencing the range of participation by people with mental distress. Whilst Beresford has progressed the underpinning values and principles of the survivor viewpoint significantly, his studies can read as if he were reporting the votes of representative samples, for example 'There was significant agreement' (2012, p.160), 'there was strong support for' (2012, p.161, interpreting Beresford et al, 2010), rather than exploring the qualitative experiences of this diverse social group in replicable ways, as the present study attempts.

Plumb's (1993; 1994; 2012) research methods combine epistemologies from survivor groups with her personal experience of mental distress in analyses influenced by Foucault's highlighting of dominant norms and Scheff and Goffman's work on stigma, and including critique of Beresford (notably in 2012). For Plumb, whilst all people may have been emotionally hurt, for some this will

have a particular character or severity, related to their life circumstances: 'Mental distress is not just about our behaviour being limited/barred by our society and culture. Distress arises out of our personal, social, cultural circumstances' (2011, p.22); so mental distress may be material, yet relational.

For Plumb, overcoming social injustice for people with mental distress requires changing the oppressive character of the mental health system; helping society become less stigmatising, less threatening to the self and more inclusive of atypical experiences; and changing personal social relations for people with felt distress. Her social perspective is normative, suggesting the need to change both the social context that drives some people mad, and the society which excludes those who express madness. As she succinctly put it: 'our demands are for a *changed society*, and room for people who do not wish to join the 'mainstream'!' (1994, p.11, her emphasis), echoing Beresford's (2004, p.218) argument that people with mental distress are 'frequently dissident, non-conformist and different in their values from dominant societal values'. This social group therefore offers a prospective 'limit test' for how capacious the capabilities approach is towards social justice for people that may act contrarily to the dominant social norm, and where limits need to lie in order to maximise agency and diversity with securing social justice, including securing life itself.

Survivor-influenced research can be ambivalent over whether analysis of the subjective experience of mental distress matters, and that instead the analytical focus should rather be on oppression by the psychiatric system, so sidestepping the issue of the 'reality' or otherwise of distress. But as Tew et al argue (2006, pp.11-13), this position is in conflict with taking user accounts seriously, and holds the risk of leaving the analysis of the internal experience of mental distress dominated by the medical sciences, a methodological challenge taken up by the present study.

Tew (2011), also influenced by survivor perspectives but writing for practitioners, seeks to open up dominant assumptions of medical categorisation, arguing that 'disruption of our personal agency' is 'perhaps the defining characteristic of all forms of mental distress' (2011, p.29). Combined with the argument that 'Breakdown is never total, and some areas of functioning may be more affected than others' (2011, p.31), he presses for a more fluid, partial,

and full account of subjective mental distress. Acknowledging the individualisation and implied normativity of dominant definitions, such as those of the World Health Organization (2011, p.18), and processes of labelling, stigma and inappropriate medicalisation including due to challenges to rationality (2011, pp.101-102), Tew positions his model as a social *approach* to mental distress. This constitutes a social explanation of onset of mental distress, which can then redouble due to social responses to the individual with mental distress, heightening the originating distress experience. His social approach resonates with Beresford's concern for the social consequences of being seen as 'other' and the work of Foucault, Scheff and Goffman, but Tew's concluding 'triple whammy' argument (2011, p.104) - experiencing mental distress, experiencing stigma, then internalising stigma - risks reducing the 'problems in living' (Szasz, 1960) experienced by people with mental distress to stigmatisation, without effectively incorporating the implications of Szasz' questioning the underpinning conceptual framework of 'mental illness' or the role of dominant social norms stemming from Foucault.

So survivor-influenced research can hold a peculiar opaqueness of the user voice beyond a particular 'survivor' experience, and can diminish normativity in terms of, for example, the potential importance to some people with mental distress of the role of the mental health system in terms of preservation of life. The focus on critique of the dominant psychiatric model and system can lead the field of study to a position in which people with mental distress can appear to be labelled by the system, leading to social injustice. This risks marginalising the inequalities across social groups evidenced in the macro-level studies, and diminishing the role of multiple wider influences on social injustice beyond the mental health system itself, as identified by, for example Rogers and Pilgrim (2003). However, the principle in survivor-influenced studies of acting as a 'countervailing force to experts' control and production of knowledge' (Rogers and Pilgrim, 2003, p.186) is accounted for in the present study through the underpinning research questions (introduction) and through the methodology (chapter four).

For Rogers and Pilgrim, the foregrounding of the user voice as a countervailing force has led to some studies that have connected 'with the broader everyday life experiences of individuals' (2003, p.187), such as those of Parr (2008),

Barham and Hayward (1991) and Estroff (1981) which have highlighted 'the wider meaning of mental distress in the lives of patients discharged to live in the community' (2003, p.187) and their navigation of identity in the context of their inpatient experience.

Barham and Hayward used group interview, individual interview and one in-depth case study to reveal the social injustices of their sample of twenty-four people living independently. Their participants had difficulty in securing trust and respect and in re-establishing a reliable material foundation in life, leaving them in a 'predicament' between becoming a 'person' first and 'mental patient' second, or vice-versa (1991, p.70). The material losses from hospitalisation for their mostly economically poor sample, including of housing security and choice, work and income, added to the loss of human respect, had a cumulative impact on their social justice.

What they achieve is a focus on a group of people with mental distress who lacked resources to pull them out of their social injustice, enabling a sociological focus on the forces that left them excluded. This approach contrasts with the current dominant narrative of hope and recovery (e.g. Scottish Recovery Network, 2006) which tends to individualise and avoid engagement with those for whom recovery may be partial in the extreme. Barham and Hayward's focus on a deeply excluded group was extremely powerful and their analysis using Dahrendorf's conflict theory and Charles Taylor's moral theory to interpret their empirical findings added weight to their interpretation of the socially unjust positions which their participants experienced in the community. However, they took 'schizophrenic illness' (1991, p.1) as a fixed variable for recruitment, collapsing into medicalisation.

Parr (2008) used in-depth interviews and ethnography with participants in rural, artistic and technological community spaces in Scotland, in order to explore the impact of recovery and community care on how lives are lived, using theories of social inclusion and geographies of difference to interpret her findings. She aimed to re-cast Goffman (1961) but outside institutional spaces. She recruited through the voluntary sector, and whilst avoiding Barham and Hayward's flaw of recruitment by diagnosis (2008, p.30) used the similarly medicalised trope of 'people with severe and enduring mental health problems' (e.g. 2008, p.26).

Whilst she found that social inclusion was ‘not completely predicated on their financial resources’ (2008, p.180) access to other material resources that enabled people to participate in activities helped; suggesting that, comparably to the capabilities approach, income is not the only resource that matters in being able to be and do valued activities (chapter three). Although her study reaches in to the ‘public’ dimensions of her participants’ lives, the role of family relationships and intimacy are underplayed in her study, as are the aspirations of people that are not involved in these very particular cultural activities.

Both studies, through transparency of recruitment and sampling processes, achieve an openness missing, for example, from Beresford et al (2010). The excavation of everyday lived experiences with which these two studies engaged whilst applying theory to draw out substantive critique and categorisation is also the aim of the present study.

Through the participation of people with mental distress in framing and interpreting studies, survivor-influenced approaches have revealed the centrality of oppression, and the particular role of the mental health system in this. Their critique is that the dominant psychiatric model denies meaningful choice, reinforces the dominant narrow behavioural norm, so oppressing freedom, and that it has not aided people with mental distress in achieving social justice. Social perspectives have provided an ontological and epistemological response to dominant psychiatric and epidemiological research conducted on service users (Rogers and Pilgrim, 2010, p.255). Their focus on oppression and discrimination has been taken up by the anti-stigma campaigns and survivor-led critiques of diagnosis, medicalisation and coercion are now followed by post-psychiatry (e.g. Bracken et al, 2012; Dowrick, 2009a). Survivor-influenced research has also influenced the ontological, epistemological and methodological position of sociological analyses of mental distress (e.g. Barham and Hayward, 1991; Parr, 2008).

Despite these openings, Beresford (2012, p.159) notes that social understandings still lack a model with the power to explain disadvantage and with the potential to transform the way that people with mental distress are socially perceived. Tew (2011, p.2) argues for the development of a coherent body of theory supported by evidence to explain disadvantage experienced by people with



mental distress. The medical model of diagnosis remains predominant and macro level social injustices experienced by people with mental distress suggest that discrimination based on dominant social norms still needs addressing but with an analysis that can also account for social determinants and social gradients shaping experience of mental distress; a fuller analysis is needed.

## **2.7 Critical realism – seeking a least reductive analysis**

This study does not explore critical realism in its entirety but applies its core concepts, following the proposition by the school's foundational thinker, Roy Bhaskar that one of the roles of philosophy is to act as 'the under-labourer, and occasionally as the mid-wife, of science' (Bhaskar, 1978, p.10). A critical realist approach accepts that subjectivity is important but is not 'value free'; theories of reality are socially constructed. This demands a method that accesses discourses, perceptions and meanings, but which strives for objectivity within this, consistent with the critical realist position that there is a material base beyond the discourse. Theory is crucial for interpreting and explaining this relationship between construction and reality, and causal explanations are based on an understanding that the social world includes underpinning social structures, powers and mechanisms. (Porpora, 1998; Bhaskar and Danermark, 2006).

Porpora (1998) has evaluated how critical realism interprets the notion of social structure in a less reductive manner than former conceptualisations used in social science. He highlights the arrangement of social relationships in the world, understood as stratified and as structured by rules, norms and ideology. He argues that these must be analysed non-deterministically (1998, p.339) in order to account for the interaction of structure, rules and relationships, and human behaviour or agency which together imperfectly reproduce social relations. This layered analysis, with Porpora seeking to overcome the limitations of competing social scientific ontologies, is compatible with the critiques of social scientific interpretations of lived experience of mental distress made earlier in this chapter.

Bhaskar and Danermark (2006) develop the critical realist understanding of a layered analysis of social reality further using the concept of a laminated

understanding. For Bhaskar and Danermark (2006) critical realism suggests a framework for social scientists to consider all scales from micro to macro whilst incorporating structure and agency to create a 'laminated' and emergent explanation of a social world (Bhaskar and Danermark, 2006) that is empirical (observably experienced), actual (events and experiences caused by the mechanisms of the real) and real (containing causal mechanisms independent of our perception) (Williams, 1999, p.806; Bergin et al, 2008, p.171). It has a normative concern for how lives are actually lived, or what people are disposed to be and do (Bhaskar, 1979, p.123), and a normative aim of explaining social injustice for the purpose of human emancipation (Watson, 2012, p.102). Critical realism is positively influenced by Marxist thought. It understands the world as non-determined, with humans reflexively deliberating on actions in response to structure with the potential to comply or subvert, so incorporating agency.

Bhaskar and Danermark have argued that in a critical realist analysis, physical, biological, physiological or medical/clinical, psychological, psycho-social, socio-material, socio-cultural and normative elements 'are all essential to the understanding of the phenomena in fields such as disability research' (2006, p.289). For them, using a social, medical or cultural framework for disability research is reductionist, avoiding 'essential complexity' (2006, p.295), as this chapter has suggested for other frameworks conceptualising the experience of life with mental distress. Consistently with Porpora (1998), they argue that using critical realism as an ontological and epistemological approach enables the construction of a 'coherent narrative that maximises explanatory power' (2006, p.292). However, whilst they apply critical realism (2006) to analyse a single case study of a hidden impairment, suggesting the potential for applying the approach in primary research, this provides a very limited example.

Rogers and Pilgrim note the focus of critical realism on both the ontic fallacy - the risk of ignoring cognitive and social mechanisms which produce knowledge from antecedent knowledge, instead relying on 'raw perceptions' (2010, p.18) as a positivist analysis might - and the epistemic fallacy of 'assuming that reality is what we call it (in the case of diagnostic psychiatry 'schizophrenia', 'depression' etc.)' (2010, p.18). Further, they argue that as critical realism provides a materialist rather than idealist basis for social science - incidentally making it compatible with Amartya Sen's (2010) notion of pragmatic versus ideal versions

of philosophy - it can accommodate both materiality of mental distress and critical analysis of the interests being served by the way in which mental distress is conceptualised by society at a given point in time (2010, p.17). These critical realist critiques encompass Foucault, Szasz, Scheff and survivor perspectives in particular.

The recent critical realist 'turn' seeks to overcome the limits of the earlier sociologies of mental distress, and this section explores studies by Rogers and Pilgrim (2003), Pilgrim and Bentall (1999), and Scambler (2006).

Reviewing secondary literature and data, Rogers and Pilgrim (2003) found, similarly to Foucault earlier, that in the mental health system power imbalances sustain coercion by mirroring '(usually implicitly) the normative concerns of the social order both parties inhabit', so (2003, p.181):

Voluntary and coercive control coexist in psychiatric practice at any particular time ... Thus, when any person presents themselves or is presented by others to psychiatric attention, they enter a social space in which an inequality of power operates.

However, unlike for Foucault, because of their critical realist ontology this is not the end of the story. With Foucault, they saw madness as elemental to the human condition (2003, p.8). But, like Plumb, they also contextualised the social inequalities and personal vulnerabilities that may lead to people experiencing 'fear or misery' (2003, p.8), and they accept that there may be a role for psychiatry in this context (2003, p.182):

Mad people break rules and miserable people withdraw from their roles. When it is successful, psychiatry reverses these social processes.

Their critical realist analysis seeks to avoid reductionism, thus macro-level data is included, which, for example, is marginalised in strongly service user influenced accounts and in Foucault; but they also bring in a critique of knowledge underplayed in the medical model. Rogers and Pilgrim's explicit normative approach reflects Sayer's (2009) argument for an effective critical social science, with which he suggests the capabilities approach is also compatible (chapter three). They use critical realism to produce a least

reductionist analysis of social justice and mental distress in a new way. However, their study did not include any primary research.

Pilgrim and Bentall's (1999) analysis revealed contradictions in medical definitions of depression, suggesting that 'distress' (1999, pp.267, 271) or 'misery' (1999, pp.271, 272) would be stronger epistemological starting points for understanding this dimension of human experience, avoiding the epistemic fallacy in which, in short, the label is not the experience. This argument again reverts the character of sociological study back to the understood nature of humanity, also foci for Nussbaum (2006) and Foucault (1967; 2009). Pilgrim and Bentall use the approach as a critique, rather than to conduct primary research.

As noted earlier, Scambler (2006) argued in relation to Goffman's *Stigma* (1963) that a critical realist approach was required both to fully account for structure that shapes definitions of the situation, and to allow for agency and contingency in 'open systems' that do not assume that people will behave according to their presumed social position. Scambler is clear that outcomes are always partial, or non-determined, a critical realist position that coincides with the argument of Amartya Sen that quality of life has an 'essential ambiguity' inadequately captured methodologically by deterministic, resource-based measures (1993, pp.33-34). Shame and stigma tend to be reproduced during social encounters, and for Scambler this requires a theory of exploitation and a theory of oppression, as 'the disadvantage sometimes accruing to those regarded as shameful through stigmatization is more often than not mixed in with, even secondary to, exploitation and oppression' (2006, p.292). Critical realism offers such a possibility.

A critical realist ontology therefore has the potential to explore tensions within lived experiences of mental distress that remain unresolved by existing epistemological claims. These include tensions between: subjective experiences of mental distress and diagnosis of 'mental illness'; oppressive versus supportive roles of the psychiatric system and related laws; liberating versus stigmatising impacts of a diagnosis or label; relieving versus distressing dimensions of psychiatric medication and its iatrogenic effects; and diverse social justice experiences related to experiencing mental distress in a specific social, economic and cultural context. However, it has been applied primarily as

critique of the limits to existing studies, and the present study requires a model of conceptualising social justice that is both compatible with sociologies of mental distress and with a critical realist ontology, so unifying analysis in a primary study. A theoretically-informed model is needed to draw these sedimented layers of research together, respecting concepts of diversity, agency, social relations and structure, the laminated influences on lives of people with experience of mental distress.

## **2.8 Conclusion: the research gap**

The review has demonstrated that there is significant complementarity between these layers of sociological analysis of social justice experiences and outcomes for people with mental distress. Responding to the dominance of the medical model and coercive dimensions of the psychiatric system which macro-level studies suggest had not resulted in social justice for people with mental distress, the conflict theory-based structuralist literature provided critical thinking on dominant social norms and professional powers that resulted in social injustice, with symbolic interactionist and social constructivist studies demonstrating the potential impacts of these at a micro-level. Both types of study then influenced survivor-based literature which has foregrounded ‘survivor’ experience of the psychiatric system, whilst holding its own reductionism due to its focus on the oppression of the psychiatric system to the exclusion of potentially diverse lived experiences of that system and other potential determinants of social injustice. This has resulted in the current critical realist ‘turn’ which aims to incorporate all perspectives, whilst holding a normative purpose to explain social injustice for the purpose of human emancipation.

So, several gaps in the sociology of mental distress are clear from the above analysis.

a. The purpose of the field has been to critique the oppressive dimensions of the medical model and psychiatric system. This means that they risk underplaying evidence of people with mental distress for whom the mental health system has facilitated wellbeing or social justice, and underplaying influences on social justice outcomes from outside the psychiatric system.

- b. Subjective experience of mental distress and diverse experiences of the psychiatric system have been avoided or explored very cautiously. This means that understanding of the agency of people with mental distress is underdeveloped, and that a model of analysis that can better account for this, and its corollary of diversity, is required.
- c. These sociologies can hold normative ambiguity in relation to increasing human flourishing and decreasing human suffering (Sayer, 2009). Where survivor-influenced social perspectives do have a shared explicit or implicit normative aim to increase social justice, they lack explicit analysis of this. This has resulted in an undertheorised understanding of social justice for people with mental distress.
- d. Whilst macro-level studies provide an indication of social injustice generally experienced by people with mental distress, they do not explore the level or types of resources required to convert socially unjust into socially just outcomes for people with mental distress.
- e. Everyday 'mundane' social justice experiences have tended to be overlooked by the sociology of mental distress, a result of the focus on critique of the medical model and psychiatric system, potentially missing the everyday micromarkers that make social justice differences for people living within wider dominant social norms and structures. Recent theoretically informed studies such as Barham and Hayward (1991) have started to address this.

The next chapter discusses how the capabilities approach can be extended by sociology and applied as a mechanism for reconceptualising the lived social justice experiences of people with mental distress in order to achieve a fuller ethical-normative understanding of the lives of people with mental distress than existing sociological approaches have allowed.

## **3 The capabilities approach – a sociological critique**

### **3.1 Introduction**

There is substantial literature using sociology to explore conceptual and empirical dimensions of mental distress. One recent model increasingly discussed in sociology (e.g. Sayer, 2012; Holmwood, 2013) and social policy (e.g. Dean, 2009; Burchardt and Vizard, 2011; Walby, 2012) is the capabilities approach, originated by an economist, Amartya Sen and a philosopher, Martha Nussbaum. Several scholars suggest that capabilities can and should be applied to normatively conceptualise lived experience of mental distress (e.g. Hopper, 2007; Davidson et al, 2009; Wallcraft, 2010), but this task is so far little attempted, especially in the UK. As mental distress has tended to fall off the edges of empirical and theoretical work in the sociologies of health and disability, so the capabilities approach has thus far left the social justice experiences of people with mental distress relatively underexplored (Martha Nussbaum, personal correspondence, 26 May 2014). The chapter argues that such a study can inform the development of the capabilities approach as well as providing an original paradigm for conceptualising the lived experience of mental distress.

The aim of this chapter is, first, to identify the normative approach to social justice that underpins the capabilities approach. Second, to establish the central concepts used within the capabilities approach, taking a critical approach to the concept of Conversion Factors in particular, and including the domains and thresholds concept originated by Nussbaum and applied in particular by Wolff and deShalit (2007) and Burchardt and Vizard (2011) in the UK context.

Third, it locates how the application of sociology can overcome ontological, epistemological and methodological constraints of extant capabilities-led studies, enabling compatibility with critical social science (Sayer, 2009). Finally the analysis demonstrates how a capabilities-framed study is compatible with social perspectives on mental distress and can achieve a less reductive, participatory and ethical-normative understanding of the lives of people with mental distress, developing existing sociological approaches.

## 3.2 Capabilities approach – philosophical base and core concepts

### 3.2.1 The normative approach to social justice that underpins the capabilities approach

The capabilities approach (Sen, 1980) is an analytical framework or partial theory of social justice (Sen, 1992, p.87; 2009, pp.296-298; Nussbaum, 2006, pp.75-76) that considers the state in which a person is actually living (functioning) and their practical opportunity (capability) to make alternative choices from a capability set. It is therefore a measure of quality of life and wellbeing with an integrated notion of equality and an integral focus on agency, a core issue for people with mental distress (Davidson et al, 2009). For the avoidance of doubt, Sen makes it clear that income matters absolutely and fundamentally to freedom and wellbeing, since ‘...inadequate income is a strong predisposing condition for an impoverished life’ (1999, p.87).

The concepts of capabilities and functionings are fundamental in a capabilities understanding of social justice. Sen defines capabilities as ‘the substantive freedoms [that a person] enjoys to lead the kind of life he or she has reason to value’ (1999, p.87). Nussbaum (2006, p.70) defines capabilities as ‘what people are actually able to do and to be, in a way informed by an intuitive idea of a life that is worthy of the dignity of the human being.’ As Hopper (2007, p.874) puts it, in one of the few papers bringing together mental distress and capabilities: ‘Capabilities are substantive freedoms, the potential to do or to be something that is social[ly] valued’. Justice is furthered when people enjoy more capabilities or freedoms to live a life they have reason to value. In capabilities analysis it is the practical, rather than theoretical, ability to make socially valued choices that indicates quality of life.

Sen (1993, p.31, his emphases) clarified the differences between capabilities and functionings:

*Functionings* represent parts of the state of a person - in particular the various things that he or she manages to do or be in leading a life. The *capability* of a person reflects the alternative combinations of functionings the person can achieve, and from which he or she can choose one collection. The approach is based on a view of living as a



combination of various ‘doings and beings’, with quality of life to be assessed in terms of the capability to achieve valuable functionings.

So functionings are what a person is actually being and doing in life, the capabilities that they are actualising, or the ‘*actual living* that people manage to achieve’ (Sen, 1999, p.73, his emphasis). For example a person with mental distress may be inadequately housed, on a low income, on medication with disruptive iatrogenic effects, and attending an outpatient clinic; or they may be in a high paid job, living in a comfortable house, on no medication and seeing a psychotherapist.

The capabilities approach has been applied internationally by the U.N to conceptualise the Human Development Index, beyond the limits of GDP (Sen, 2000). It has been applied domestically in The Equalities Review (2007), the Equality and Human Rights Commission (EHRC) developing an Equality Measurement Framework (Alkire et al, 2009) as a means of evaluating inequality and freedom in the UK. Boardman (2010) has suggested that the domains listed for conceptualising and measuring inequality in the Equalities Review (2007) ‘provide a useful means of listing the areas in which people with mental health problems experience discrimination and exclusion’ (2010, p.35) enabling judgment of real opportunities and substantive freedoms, and ways in which action may be taken to enhance these.

From the outset Sen (1980) made three arguments. First, that theories of equality must apply to the reality of the social world as is, so what matters in evaluating justice is what people in the world are actually able to do and be, looking at ends (lives lived) rather than means (e.g. money). Second, that the social world incorporates diverse people, including disabled people and people with different health needs, and this must also be taken into account: social justice theory can neither assume that everyone has equal power or can create the same outcome from the same set of resources. Third, that moral philosophies of equality also need to take into account the world as should be; this needs to include a concern for equality. Venkatapuram (2014, p.413) notes that it would be ‘antithetical ... if the concept of capability was used but then aspects of equity were disregarded or violated’.

The capabilities approach is, then, an explicitly normative philosophy (Sayer, 2009), aiming to increase social justice for oppressed groups (Sen, 2010; Nussbaum 2011). It aims to provide a fuller account than, for example, welfarist or specifically utilitarian resource-based evaluations of wellbeing, or subjectivist accounts of wellbeing (e.g. Layard's (2005) happiness agenda, Sen, 2010, pp.273-275) on the basis of their lack of account of adaptive preferences and their reductionism ('the claim that nothing else matters - liberty, equality, fraternity or whatever' (Sen, 2010, p.274)). By evaluating how people are actually able to live, what they can actually do and be, capabilities develops an objectivist account (Sayer, 2011, pp.233-234), yet incorporating resources and also some dimensions of subjectivity.

Sen has persistently used disabled people and people with additional health needs as examples of people experiencing social injustice (e.g. 1980, p.215; 1992, pp.28-29, 83-84; 2010, pp.256-260, 306-307), as has Nussbaum (e.g. 2006). Whilst this suggests a potential compatibility with the concerns of the survivor movement for the equality of these groups, the development of the capabilities approach by Sen and Nussbaum emerged in parallel to disability studies and the sociology of mental distress, and is the weaker for this. From the perspective of disability studies its development by Sen has tended towards a pitying and essentialising view of disabled people, using them as ethical arbiters: 'cripples' are used in his early work as exemplars of disadvantage and economic inefficiency (e.g. 1980, pp.213-214), the 'mentally disabled' are not in a position to 'exercise reasoned freedom of choice' (1993, p.44), and 'people so handicapped in terms of personal characteristics (e.g. being a 'basket case')' will be 'invariably defined as poor' (1993, p.42 n.35), blurring physical impairment and mental distress in a way liable to elicit feelings of pity, fear and disgust (Hughes, 2012). He makes a binary and universalising argument divorced from the reality of changing social relations, contradicting his claimed ontological perspective on the world as emergent, complex and partial. Sen developed this position later (e.g. 2010, pp.258-260), yet he returns persistently to the generic disabled person who cannot efficiently convert means into ends (e.g. 1992, pp.20, 28, 81, 91; also 1999; 2010). There is, for Sen, inevitably a penalty for impairment itself, in contrast to an analysis of how the social

relations of impairment may engender social injustice, which would be more in tune with social perspectives on mental distress as seen in chapter two.

However, Sen demonstrates an opening for a more critical approach to inequality, returning to the purpose of his critique of resource-based accounts as an ‘attempt to take direct note of a person’s difficulties - *naturally or socially generated* - in converting ‘primary goods’ into actual freedoms to achieve.’ (1992, p.148: my emphasis). In his earlier work, Sen drew in pre-existing economic inequalities, in addition to the social dimension (1992, p.27):

We differ not only in terms of our inherited wealths, but also in our personal characteristics. Aside from purely individual variations ... there are also systematic contrasts between groups...

Also: ‘The societies and communities to which we belong offer very different opportunities as to what we can or cannot do’ (1992, p.20). It is of note that this analysis of inherited injustices disappears in his characterisation of ‘Conversion Factors’ in his later work (e.g. 1999; 2010), in which the focus becomes on ‘remediable’ factors, limiting his analysis: ‘the presence of remediable injustice may well be connected with behavioural transgressions rather than with institutional shortcomings’ (2010, p.x). The sociology of mental distress suggests that the two are connected. Unlike, for example, Foucault, Sen does not pursue where dominant social norms and relations emerge from or how they become reproduced institutionally, his pragmatism retreating only to their empirical existence, evaluation and remediation. A higher level analysis using sociology may enable a least reductionist capabilities explanation of injustice experiences of people with mental distress.

Martha Nussbaum has developed Sen’s conceptualisation of capabilities. Arguing in *Frontiers of Justice*, the prime text on capabilities and disability, that disabled people, defined as ‘people with physical and mental impairments’ (2006, pp.1, 420 n.37), had never achieved social justice under existing dominant moral philosophies, including the social contract and related Rawlsian theories of justice (2006, pp.1-2), she suggested that a reshaping of theoretical structures was therefore required to account for the inherent dignity of all humans including disabled people.

Nussbaum has consistently questioned binary notions of disabled/non-disabled and normal/impaired in relation to experiences of mental and physical impairment in her advocacy of her capabilities approach (e.g. 2006, pp.92, 99), overall revealing a less deterministic approach than Sen. Several times she sets out detailed scenarios describing the social constraints on impaired people and the social construction of these, in which it is the norms of society that define people as disabled and it is these norms that require changing (e.g. 2006, pp.110, 112-113, 116-117, 165, 222). Despite her lack of engagement with the sociology of mental distress, these are compatible with social perspectives.

Nussbaum also argued from Aristotle and Marx that rationality and human 'animality' are 'thoroughly unified' (2006, p.159). In turn, 'the capabilities approach sees the world as containing many different types of animal dignity, all of which deserve respect and even awe' (2006, p.159). Accompanying this, sociability was equally fundamental and 'bodily need, including the need for care' (2006, p.160). These remarks hold an implied compatibility with Foucault's (1967; 2009) understanding of the human, and with elements of survivor literature. First, about the need for society to more strongly embrace diversity. Second, that human diversity contains many interpretations of rationality. But third, that the need for human care is a fundamental part of human life - and we can read 'bodily need' liberally - as 'rationality and sociability are themselves temporal' (2006, p.160) and thus vulnerability comes and goes for all humans. She argues that needing care is part of being fully human, and that all humans experience vulnerability.

However, Nussbaum's analysis in *Frontiers of Justice*, perhaps influenced by her background in gender politics, persistently (2006, Chapters 2 and 3, throughout) took caring relations as the core theme for analysis of the experiences of disabled people. This reinforces notions of disabled people having a core need for care, rather than, for example, core needs of employment, family life, freedom of movement and so on, buttressing a passive and dependent stereotype of disabled people, critiqued by Alexander and Hopper (2007, p.13) in the context of mental distress. Most problematically her analysis took a non-problematized view of both care and Guardianship (2006, pp.199, 218), which have been historically riven with tensions (e.g. Barnes and Mercer, 2010, Chapter 6). Nussbaum suggests that care is personal and familial, rather than

institutional, and her omission of the experiences of people with mental distress and the distinct history of labelling, incarceration and removal of civil rights under the aegis of caring-as-protection is striking. As she subsequently notes in the same context, the debate ‘about mental illness is actually a much more difficult debate in this area, because people still tend to blame mental illness on the ill person’ (2009, p.339). Her lengthy analysis is therefore limited in the extent to which it can integrate the experiences of people with mental distress.

Nussbaum’s (2006) analysis eliminated any analytical distinction between learning disabilities and mental distress, generalising across the two categories. In the sociological literature the two are discretely understood both theoretically and empirically whilst recognising that the two are not mutually exclusive. Both categories were incorporated by Nussbaum within the term ‘mental impairment’, but her acknowledgement of mental distress was tokenistic at best: people with mental distress may experience extreme dependency on others ‘during a period of depression or acute mental stress’ (2006, p.101); and Rawls’ account of justice excludes those with ‘severe mental illnesses (including severe depression)’ (2006, p.112), implying that hers did not repeat this. Nussbaum’s eradication of the distinction means that potentially important differences in lived experience between the two groups were made impossible to distinguish. She is able to sustain her argument throughout the book only because she applies it solely to people with cognitive impairments and therefore makes a claim for her analysis that is only partially met. People with cognitive impairments may provide less of a challenge to capabilities’ conceptual underpinnings than people with mental distress whose experiences may be more fluctuating and hard to categorise, whose world-view may challenge notions of freedom and rationality, and whose relationship to caring is distinctive.

In an interdisciplinary work on capabilities, health and social justice blending Senian and Nussbaumian approaches, Venkatapuram (2011) has underscored this critique, arguing that there is more to consider in terms of social justice than adequate care, namely the social determinants of what he terms ‘avoidable impairments’ (2011, p.151; also acknowledged by Sen, 2010, pp.258-260). He argues that changes to ‘...social institutions, processes and values’ (2011, p.152) are required to secure social justice, compatible with arguments throughout the

sociology of mental distress in Chapter two, above, and further emerging in Section 3.2.4, below, on Conversion Factors. Venkatapuram added that Nussbaum's account of social justice missed 'the most current research and theories of causation and distribution of impairments and mortality' (2011, p.150), suggesting that instead Nussbaum's analysis handles disability 'as a stable, inherent trait of individuals' (2011, p.151). The evidence of social determinants and social gradients for mental distress was set out in Chapter two, above.

Nussbaum's most distinctive contribution to capabilities has been to introduce a particular, more objective, normative account of human functioning and its evaluation, the concept of a set of ten central human capabilities (2011, p.36):

The basic claim of my account of social justice is this: respect for human dignity requires that citizens be placed above an ample (specified) threshold of capability, in all ten of those areas.

A 'decent political order must secure' these for its entire people (2011, pp.32-33) in order to secure social justice. Her list is defined in a 'thick, vague' way to enable local interpretation. So, for those that are distanced from attaining socially just lives in any given society, capabilities is about the demands that may be made to 'compel social action to address these constraints as a matter of social justice' (Venkatapuram, 2009, p.411). Thus, capabilities is about how societies and states should be organised to better provide for the social justice-as-capabilities of all citizens.

Sen, whilst resisting following Nussbaum's path of proposing a list of central capabilities (e.g. 1993, p.47), also acknowledges a need for public reasoning in defining the most valuable capabilities in a given society. This participatory dimension is a methodological and ethical commonality for the two philosophers, coinciding with participatory principles from the survivor movement influencing studies with people with mental distress.

Sen's approach to evaluation has instead been more open, on the basis that an underlying idea such as quality of life has an 'essential ambiguity' methodologically, which must also be captured by capabilities (1993, pp.33-34). Suggesting that capabilities analysis must also be incomplete as the 'metaphysics

of value’ (1993, p.49) were open to interpretation by different substantive ethical theories with which the capability approach is ‘consistent and combinable’ (1993, p.48), Sen argued that the capabilities approach does not hold an ethical monopoly. It therefore has the potential to be combined with a critical realist ontology (as, for example, by Tao, 2013).

Despite Sen and Nussbaum’s critiques of utilitarian and welfarist principles of justice, resources are also central in capabilities analysis, but they are only the starting point for evaluating actual social justice outcomes. Capabilities assumes that people have a personally variable set of resources on which we can draw, such as physical and mental attributes, income and other assets, and public goods and services. However, core to capabilities is the understanding that the social justice outcomes which people attain are also influenced by a series of other factors. The mix of freedoms and opportunities implicit in capabilities are a combination of personal resources and the political, social and economic environment (Nussbaum, 2011, pp.20-21). So, whilst capabilities is concerned for the wellbeing, indeed flourishing (Sayer, 2011, p.234), of each individual citizen, it is not an individualised framework, it is relational.

Venkatapuram’s definition of health justice (2011, p.20), reframed for this study as social justice (see Chapter one), is compatible with the social perspectives discussed in the last chapter, in which, as for Venkatapuram (e.g. 2011, p.5), it is the social arrangements that tend to lead to injustice for people with mental distress which are in question. The definition is also compatible with Sayer’s (2009) argument for a critical social science with regard to flourishing and suffering. In the context of mental distress, this enables development of social perspectives by taking evaluation of social justice beyond narrow arguments about social constructivist versus medical models, the overly strong focus on the mental health system as the cause of social injustice, and assumptions of universal psychiatric oppression. It liberates the sociology of mental distress, forcing attention onto the actual social justice outcomes of people with mental distress as part of society as a whole, the normative aim of the capabilities approach.

So the capabilities approach contains a set of core concepts to be drawn together in ‘evaluating equity across multiple dimensions’ (Venkatapuram, 2009,

p.413) in the complex circumstances of the real world. As with survivor-influenced studies, interpretations of all capabilities concepts have some variance. Those selected and interpreted below are those that are most central to capabilities as an analytical framework, combined with those concepts that resonate with the social perspectives literature in the last chapter.

### **3.2.2 Capabilities, capability set and capability deprivation**

Developing the definition of capabilities provided earlier, Sen has argued that although capabilities include the more universal substantive choices such as ‘the ability to be well nourished and well sheltered, the capability of escaping avoidable morbidity and premature mortality’ (1993, p.31), capabilities required for a dignified life will vary by society. Sen suggests that in ‘richer countries’ (1987, p.30) capabilities - and functionings (see next section) - might include (1987, pp.30-31):

The ability to entertain friends, be close to people one would like to see, take part in the life of the community, etc., may vary a good deal ... There are other functionings (for example, those involving literary, cultural and intellectual pursuits on the one hand, and vacationing and travelling on the other) which involve a good deal of variation ... and which raise questions of assessment and evaluation.

This gives a sense of the breadth of socially valued choices included by capabilities in defining social justice, demonstrating that capabilities takes the analytical field of concern beyond, for example, basic needs analysis (Sayer, 2011, p.234), into a conception of human flourishing, from food and shelter to participation in social life. The inclusion of entertaining people at home, reading, culture and holidays also has resonance with the relative versus absolute poverty debate in the UK since Townsend (1979) (e.g. Marmot, 2010, pp.120-121). So a capabilities view of the substantive choices that constitute social justice, and the health evidence coincide.

The fact that a capability is attainable does not imply that it needs to be achieved to be valuable: having the resources to go on holiday does not mean that a holiday must be taken. But not being able to choose to take a holiday, or, for example, seek a desired relationship is, in Western societies, an indicator of lack of capabilities, or what the capabilities approach calls capability



deprivation. There is some ambiguity in capabilities about the interpretation of capability deprivation - to what degree particular capabilities need to be missing from a person's life in affluent societies in order for them to lack wellbeing (e.g. Robeyns, 2005, p.101), further debated in Chapter eight. This is partially a symptom of Sen and Nussbaum's different conceptions of capabilities. However, the two can be unified and for the purposes of this study, a person is defined as in capability deprivation when they fall below threshold achievement of any one of the list of domains provided in the second part of the fieldwork.

The collection of available substantive choices that could be chosen is known as a capability set. For Sen (1992, p.150) 'The 'capability set' can be seen as the overall freedom a person enjoys to pursue her well-being.' Sen has pointed to the difficulty in operationalising capabilities (1993, pp.52-53), in contrast to functionings, due to differences in direct observability. This has been recently addressed by Burchardt and Vizard (2011), and by Wolff and deShalit (2007).

### **3.2.3 Functionings**

Social justice is also measured in terms of whether the person actually achieves functionings of a certain 'value' in contributing to a notion of wellbeing. Sen has suggested examples of functionings (1993, pp.31, 36-37), proposing that some will be 'elementary' or 'centrally important' (1993, p.31) such as being adequately nourished, being in good health, escaping morbidity and mortality, having mobility. Others 'may be more complex but still widely valued' (1993, p.31) such as achieving self-respect, being socially integrated, being happy, taking part in the life of the community, and appearing in public without shame. As Sen emphasises that individuals will subjectively evaluate the importance of different functionings, the question over which are 'the most important ones to protect' (Nussbaum, 2003, p.33) within his definition remains ambiguous. However, even in terms of Sen's 'elementary' functionings, the introduction of health sociology complicates his analysis. In his distinction between, for example, 'being in good health' and 'escaping morbidity', the former suggests a life with no ill-health, an idealistic proposition challenged in health sociology (Blaxter, 2010, pp.4-6).

Venkatapuram (2014, p.411) notes that capabilities and functionings are mutually reinforcing: 'Capabilities lead to functionings which in turn may create more capabilities and functionings'. The opposite is also true; for groups experiencing social injustice restricted capabilities may lead to limited functionings, and risk further reducing capabilities.

### **3.2.4 Conversion Factors**

Chapter two explained how the social world is interpreted in this study through a laminated critical realist ontology, with underpinning social structures, powers and mechanisms operating interactively with human agency to offer a least reductive and non-deterministic explanation of how the world is (Bhaskar and Danermark, 2006; Porpora, 1998). This section discusses and develops the capabilities concept of Conversion Factors by identifying limits to the approaches taken by selected capabilities scholars to these; adding the original contribution of structural Conversion Factors; and identifying the compatibility of multiple forms of Conversion Factor, as heuristic devices to evaluate social justice outcomes, with social determinants of mental distress and the laminated critical realist ontology framing the study.

Capabilities has persistently argued that a disabled person may need disproportionate resources or different means to achieve comparable socially valued goals to a non-disabled person. The 'impairment' of earning ability commonly faced by disabled people is magnified by the extra costs of converting income into 'good living' (Sen, 2010, pp.258-260, applied by Kuklys, 2005). People with mental distress may also have additional resource needs related to, for example, support in the community, at home, at work, or getting the right psychotherapy, and, as the macro-level evidence suggested, also problems in gaining sufficient income.

Sen's persistent point, at least since 1987, has been that by focusing on income poverty alone, analysis of the social world may entirely lose 'crucial aspects of deprivation' (1992, p.113), associated with 'contingent circumstances' or 'circumstantial variations' (1999, pp.70, 88, 110). These dimensions have become known as Conversion Factors, which Nussbaum argues 'matter most for social justice' (2006, p.75).

Conversion factors are described by Robeyns (2005, p.99) as the elements of the personal, social or environmental that allow a capability to be available and actualised. Although in the real world, Conversion Factors persistently interact, they can be separated for analytical purposes. Exploring the interpretations of Conversion Factors made in a sample of four authoritative capabilities sources (Robeyns, 2005; Kuklys, 2005; Stanford Encyclopedia of Philosophy; Trani et al, 2011) alongside Sen's work, certain common features can be observed, summarised in [Figure 1](#).

### Varying accounts of CFs

CF	Robeyns (05)	Kuklys 05	Stanford encyclop (11)	Trani et al (11)
Per	e.g. metabolism, physical condition, sex, reading skills, intelligence	e.g. sex, physical disabilities, intelligence	e.g. metabolism, physical condition, sex, reading skills, or intelligence	disabilities, skills, gender, age, etc. (151) e.g. physical conditions, sex, skills, talents, intelligence, sensitivity, interaction attitude (153)
Soc	e.g. public policies, social norms, discriminating practises, gender roles, societal hierarchies, power relations	e.g. population density, legal regulations	e.g. public policies, social norms, practices that unfairly discriminate, societal hierarchies, power relations related to class, gender, race, or caste	social norms, religious norms, sexism, racism, etc. (151) e.g. public policies, institutions, legal rules, traditions, social norms, discriminating practices, gender roles, societal hierarchies, power relations, public goods (153)
Env	e.g. climate, geographical location	e.g. climate, proximity of rivers, level of environmental pollution	e.g. climate, pollution, proneness to earthquakes, the presence or absence of seas and oceans, the stability of buildings, roads, and bridges, the means of transport and communication	living in a dangerous area, existence of a transportation system and a communication structure, schools or health services (151) e.g. infrastructure, country, public infrastructure, climate, pollution (153)

Figure 1: varying accounts of Conversion Factors

Robeyns' theoretical work asserted the assumed working of Conversion Factors (e.g. 2005, p.99), as does the Stanford Encyclopedia. These sources take Conversion Factors as a given, so they are not 'unpacked' or their veracity interrogated. In contrast, Kuklys (2005) sought to apply Conversion Factors as part of an attempt to measure how the capabilities of disabled people are influenced. She defined Conversion Factors as 'those individual, social and environmental factors that affect the conversion of resources into functionings'

(2005, p.81). Kuklys (2005, p.83) noted: 'From the capability perspective, disabled individuals suffer from lower income generating capacity and, in addition, from a lower capacity to convert resources into functionings'. Her analysis tells us that this is the case but does not explain at a full enough level why this is the case.

Trani et al (2011) explored ways of measuring the gap between functionings and capabilities for disabled people, noting in this context (2011, p.145) that: 'In order to promote capabilities of persons with disabilities, public policies affect the factors that allow individuals to convert resources and commodities into capabilities'. They explored the character of Conversion Factors for disabled people, listing a wide range of hypothetical examples (see Figure 1, column 4). They argued that Conversion Factors intervene at individual, family, community and national levels, promoting or constraining the achievement of capabilities, arguing (2011, p.154) that: '... cultural beliefs may entail social exclusion for persons with disabilities, leading to low self-esteem and isolation. In this case, it becomes difficult for persons with disabilities to "convert" bundles of resources into capabilities'. The evidence in Chapter two explained why people with mental distress tend to experience social injustice, or the conversion of bundles of resources into capabilities, an explanation associated with dominant norms stemming from the Enlightenment.

The constraint for Trani et al, as for Robeyns and Kuklys, is that not using a sociological analysis, and more particularly a layered critical realist analysis, leaves an explanatory gap: the explanation of why 'cultural beliefs' exist which oppress those experiencing social injustice or why 'disabled individuals suffer from lower income generating capacity' (Kuklys, 2005, p.83). Sociological analysis in general, and a laminated critical realist ontology in particular, can explain these 'why' questions more fully (Holmwood, 2013). This was seen in the multiple ways in which sociological analysis in Chapter two explained the largely disadvantaged social position of people with mental distress, including by bringing in analytical layers such as 'underlying structures and mechanisms', that sometimes imperceptibly underpin 'cultural beliefs' or dominant social norms that can curtail individual ability to successfully convert (Bhaskar and Danermark, 2006, pp.294-295). Embedding Conversion Factors within a laminated critical realist ontology can create the analytical space for

exploration of those features that underpin the ‘conversion’. This layer of explanation is currently left as a ‘black box’ by these capabilities analysts. To achieve this step requires bringing structural Conversion Factors explicitly into the analysis, as further explained below. Prior to this, further limits to these authors’ work on Conversion Factors requires analysis. This reinforces the analytical benefits of distinguishing between social and structural Conversion Factors, and in the process further draws out the compatibility of Conversion Factors with a laminated critical realist ontology.

The four sources interpreted personal Conversion Factors as physical elements like metabolism, physical condition, sex, and intelligence. Some also include relational elements such as disability, gender and skills. In his two most substantive works, Sen specified personal Conversion Factors as heterogeneities by age, gender, disability and illness (1999, p.70; 2010, p.255) and earlier (1992), suggesting further complexity and ambiguity, by: ‘age, sex, physical and mental health, bodily prowess, intellectual abilities ... and in many other respects’ (1992, p.28). Sociologically, some of these concepts are relational, some not (e.g. gender versus sex), and capabilities fails to explore these distinctions. Sen uses identity characteristics in an oversimplified manner, a sociological concern highlighted by Holmwood (2013, p.6).

The four sources described environmental Conversion Factors as the impact of the physical world - climate, physical location, and also transport and communication infrastructure. Whilst these factors may reflect the origins of the capabilities approach in the global south, for people with mental distress in western societies, the physical environment only affects social justice outcomes at the very margins. Where the infrastructure does influence the experience of mental distress it is in relation to a social-structural context - inadequate living conditions, being confined to psychiatric hospitals, living far from public services; in sociological terms it is analytically weak to distinguish the environment per se as a Conversion Factor in western societies.

Social Conversion Factors were exemplified by the four sources as public policies and laws, social norms, discriminating practices, societal hierarchies and power relations. Sociologically speaking, social Conversion Factors have been left holding a lot of conceptual weight, from everyday social interactions to

structural formations - from Goffman to Foucault. These examples each hold their own social policy and sociological literature, with their impacts explained in that literature by examining underlying structural mechanisms affecting the distribution of opportunities. Social Conversion Factors are also the most normatively interesting, as they include areas of public policy and practice which are most open to intervention in order to enhance social justice, and which hold duties for protecting and enhancing social justice outcomes.

All four sources imply that the examples provided for each Conversion Factor are non-exhaustive, a practice to which Sen is also prone in his writing on the topic (e.g. 2010, p.255 - 'and so on', 'for example', 'including'). Capabilities tends to *assume* an understanding of Conversion Factors. From a sociological perspective this indicates lack of clarity and of critical thought. It is not clear how the examples aid understanding of when something is not a Conversion Factor, or in judging which Conversion Factors are relevant to understanding capabilities in any given society or situation. In sociology too, structure and agency interplay, this dualism expressed as 'the way in which human beings both create social life at the same time as they are influenced and shaped by existing social arrangements' (Layder, 2006, p.5). This means that analytical concepts such as Conversion Factors are viewed as heuristic devices, in the real world inseparable, yet aiding explanation of social phenomena. So, in capabilities literature, Conversion Factors are still quite undertheorised, underplaying their explanatory and critical potential. To convert Conversion Factors to more fully and critically explain social justice outcomes for people with mental distress in a western context, more analytical work is required to distinguish the structural from the social.

Social Conversion Factors hint at those structural levels, but hold back from incorporating into the analysis the structural layer of explanation of what it is that makes social hierarchies; what it is, for example, that 'provides the rules of the game' (Wolff and deShalit, 2007, p.173) in mental health care as based on a strongly medicalised model, stemming from a dominant binary view of humanity, and from which social injustices follow (Chapter two). Or 'the rules of the game' that have led to hearing voices being seen as a breach of social norms, to be 'treated' through the dominant medical approach of suppressing voices, and

continuing to be seen in western societies as undignified or shameful, resulting in broader stigmatising social attitudes, and thus leading to social injustice.

The last chapter explained how structural forces through causal mechanisms independent of our perception (Bhaskar, 1978) shape dominant modes of thought and action. These lead to people non-consciously valuing certain social roles - and - crucially for social justice for people with mental distress, devaluing others. The resultant hierarchies have a significant impact on socially valued opportunities for people with mental distress.

If capabilities is serious about social justice it has to critique what it is that has resulted in the dominant discourses in relation to mental distress being medicalised and resulting in empirical social injustices: this dimension is fundamental to the conversion for people with mental distress. At present, it is as if these notions of social hierarchy and 'established patterns of behaviour' (Sen, 2010, p.255) simply exist and that their structural roots play no role in our ability to convert resources into 'characteristics of good living and into the kind of freedom valued in human life' (2010, p.254). The social history of people with mental distress shows that what we might call 'structural' Conversion Factors require inclusion to explain the type of social justice they experience.

So, Trani, Robeyns and Kuklys place too much analytical weight on social Conversion Factors, maintain the primary relevance of environmental Conversion Factors which are of second order significance for people with mental distress in the North West of the world, and underplay the explanation of how 'the rules of the game', or social hierarchies, are structured, which, as shown in Chapter two, has a profound effect on the social justice of people with mental distress. This demonstrates the explanatory benefit of drawing on a critical realist perspective to draw in analysis of social structures. It also suggests that the replacement of environmental Conversion Factors with structural Conversion Factors will achieve a fuller or, in critical realist terms, less reductive explanation of the conversions that shape social justice experiences for participants in this study.

So, if personal Conversion Factors for people with mental distress include the subjective experience of mental distress, alongside other dimensions that are in

the last instance held within the self, social Conversion Factors are those observable institutional and organisational features that may facilitate or constrain social justice, notably those within the mental health system, but also mainstream social institutions such as employment, income, education, family, and intimate and wider social relations. Structural Conversion Factors become the non-observable causal mechanisms that structure the way in which people interpret the world, that lead to hierarchies of social organisation and which shape what is socially valued in the world, not only the dominant norms and values related to mental distress, but also wider social valuations, for example, that employment is good, particular lifestyles are more valuable than others, and the medical system is to be trusted to serve society's best interests. Together these shape the agency and social justice of people with mental distress.

The relationship between social determinants of mental distress and Conversion Factors requires exploration. Social determinants of mental distress are complex and interrelated, as demonstrated in the context of other areas of health by Venkatapuram (e.g. 2011, p.11), and as seen in Chapter two, above. For Venkatapuram (2011, pp.154-155), the social bases of health or 'personal features/needs, behaviours, surrounding social and physical conditions' (2011, pp.154-155) require inclusion to evaluate achievement of capability thresholds by individuals. Venkatapuram (2011, p.11) also argues that the field of concern for capabilities needs to incorporate social determinants of health in a deeper sense:

The social bases of the causation and distribution of impairments and longevity are significant and pervasive whereby causal chains 'run back into and from the basic structures of society' (Hofrichter, 2003, pp.xvii-xxi). Recognizing the causal chains is crucial to recognizing the injustice in the current state of health and longevity of human beings in modern societies.

Through this understanding of social determinants, Venkatapuram incorporates a layer of explanation overlooked by Nussbaum in the context of health (Venkatapuram 2011, p.150). However, whilst successfully embracing social determinants in general, Venkatapuram (2011) does not consider, for example, the historical power of either the medical model itself nor of the dominant cultural discourses that the evidence suggests (Chapter two, above) can



negatively shape the social outcomes for people categorised into some specific health classifications, notably including mental distress. These cultural and normative elements of social determinant have an additional impact on both the agency and social justice outcomes for people within those social categories. The incorporation of these layers of structural powers and mechanisms (Bhaskar and Danermark, 2006) is necessary to construct a least reductive explanation of why people with mental distress can struggle to achieve capabilities and functionings because of how the ‘rules of the game’ (Wolff and deShalit, 2007, p.173) are structured, and can be brought into a capabilities understanding of mental distress through the explicit incorporation of structural Conversion Factors, in addition to personal and social Conversion Factors. The replacement of environmental Conversion Factors by structural Conversion Factors ensures the incorporation of this enhanced explanatory layer, whilst being compatible with analyses that use the concept of social determinants in less maximal ways. This approach is compatible with analyses based on a laminated critical realist ontology which seek to least-reductively account for these less perceptible modes of social determinant (e.g. Rogers and Pilgrim, 2003).

It is important to highlight the risk of oversimplification of social determinants through their heuristic interpretation using Conversion Factors. This fits with Sen’s (1999, p.71) finding in his interpretation of Conversion Factors that, for example, ‘Issues of epidemiology and pollution are both environmental and socially influenced’, reinforcing how some Conversion Factors are impossible to delineate into either personal or social or structural. This is reflective of the real-world engagement of the capabilities approach, and reinforces the need for a rigorous approach to interpretation of Conversion Factors, as this study seeks. The empirical examples of social determinants of mental distress explored in the forthcoming data chapters reflects this real-world combination of ambiguity and complexity, analysed using Conversion Factors, reflected on in Chapter nine.

So, the relational, self-in-society character of capabilities enables these multiple forms of Conversion Factor to be consistent with the critical realist ontology underpinning the sociological dimensions of this thesis. As seen in Chapter two, a critical realist perspective implies that the analysis of what people can do and be locates explanation in the underlying structures as well as in what is empirically observed (Porpora, 1998; Bhaskar and Danermark, 2006; Fisher,

2009). This is where structural Conversion Factors make a distinct analytical contribution. As exemplified above, delineating structural from social Conversion Factors allows the non-observable causal mechanisms which shape social hierarchies for people with mental distress to be explicitly drawn into the analysis, with their own conversion ‘weight’. This averts the risk, seen in Kuklys (2005) and Trani et al (2011), above, of the explanation of ‘why’ social hierarchies exist disappearing from the analysis, resulting in a reductive analysis with a focus on more ‘remediable’ social Conversion Factors. Instead, framing the study using critical realism allows an analytical ‘least reductiveness’ to be brought into a capabilities interpretation of social justice, and the incorporation of structural Conversion Factors enables this to be made explicit in capabilities analysis. Further, the interpretation of whether all three categories of Conversion Factor make a positive or detrimental contribution to social justice are also compatible with critical realism’s intent to analyse society as it actually exists, not assuming oppression, but demonstrating it with a normative purpose, so compatible with the capabilities approach. Finally, the critical realist laminates exemplified by Bhaskar and Danermark (2006) in the context of disability as physical, biological, physiological or medical/clinical, psychological, psycho-social, socio-material, socio-cultural and normative, are also compatible with interpreting social justice experiences heuristically using the three layers of Conversion Factor, as explored further in Chapter nine, Section 9.4.

### 3.2.5 Adaptive preferences

Sen has argued that to focus analysis on freedoms to achieve (capabilities) rather than actual achievements (functionings) ‘depends quite heavily on the knowledge and the ability of the person to understand and intelligently choose from the alternatives they really do have’ (1992, p.149). Otherwise what are known as ‘adaptive preferences’ emerge, in which people choose according to what they are socialised to expect. He further argued (1992, p.149):

If social conditioning makes a person lack the courage to choose (perhaps even to ‘desire’ what is denied but what would be valued *if* chosen), then it would be unfair to undertake the ethical assessment assuming that she does have that effective choice. It is a matter of concentrating on the real freedoms actually enjoyed, taking note of *all* the barriers - including those from ‘social discipline’.

Although the capabilities approach holds that agency is vital to wellbeing, it also acknowledges that agency is not in a vacuum. Available choices are shaped in multiple ways. These structured powers or ‘social disciplines’ may oppress or enable and all are in theory open to analysis. However, in practice, acknowledgement of this in capabilities is constrained by a lack of sociological theory to evaluate the impact on social justice of underlying structural forces.

To this Sen added a critique of utilitarian ethics for neglecting ‘the claims of those who are too subdued or broken to have the courage to desire much’ (1992, p.149). In suggesting ‘subdued or broken’ Sen strongly implies that those with particular experiences of mental distress may be vulnerable to adaptive preferences. But Sen takes the implications of this no further, due to his lack of application to the sociological literature on mental distress.

Adaptive preferences are acknowledged as a barrier to achieving social justice. The capabilities approach is conscious that preferences in life are adjusted to the level that people learn we can achieve. For example, people with mental distress may be told ‘you will never work again’, or may feel shame or self-stigmatisation leading to reduced ambition or isolation. More subtly, it may mean internalising dominant social norms about personal behaviours that restricts a person’s ability to actually ‘be free’ in public. The analysis of lived capabilities of people with mental distress may inform adaptive preferences further.

### **3.2.6 Diversity**

For Sen, ‘Human diversity is no secondary complication (to be ignored or introduced ‘later on’); it is a fundamental aspect of our interest in equality’ (1992, p.xi). Whereas medical models of mental distress operate on the basis of deviation from a dominant norm, for Sen difference is a specific variable in human capabilities (e.g. 1999, p.77; see also Terzi, 2005; Davidson et al, 2009). This principle is compatible with Plumb’s (1994) conceptualisation of different ways in which people with mental distress can be oppressed, being labelled as breaching social norms.

The diversity principle in capabilities has two dimensions. First, it acknowledges the empirical reality that humans are heterogeneous, as seen in the examples of personal Conversion Factors. Second, it acknowledges that those diverse people may value or ‘weight’ functionings and capabilities personally - so one person with mental distress may value getting work above all else, another may value finding a relationship; another may value simply staying free of distressing thoughts. This dimension of diversity challenges normativity, and in relation to the lives of people with mental distress, the capabilities approach therefore promotes self-determination (Davidson et al, 2009). This coincidentally follows principles advocated by the survivor movement.

So, people with mental distress are judged by the capabilities approach on the same metric as any other citizens. However, as people may value or ‘weight’ functionings and capabilities personally, there is not a single metric to compare wellbeing or capability sets. This can make operationalisation challenging (Mitra, 2006, p.240).

### **3.2.7 Agency and wellbeing**

Sen posits that ‘the good life is partly a life of genuine choice, and not one in which the person is forced into a particular life - however rich it might be in other respects’ (1993, p.39 n.26). Agency is of particular interest in the lives of people with mental distress who have been in psychiatric hospital, and for whom there exists a history of coercion and enforced or de facto enforced treatment based on a medical model, described by Davidson et al (2009, pp.41-42):

...the precondition held out for people with serious mental illnesses has been the need for them to be cured of their illnesses or to become “normal” before they can rejoin community life. A capabilities approach asserts to the contrary that it is only through participation in community life as self-determined agents that people with mental illnesses will acquire the capabilities needed to manage their conditions.

Davidson et al (1996) found that the loss of freedom and autonomy was the most problematic issue for people with mental distress in long-term hospital. Assessing this using capabilities (Davidson et al, 2009, p.40) found that:

...more can be done in a positive way beyond releasing someone from an institution ... to promote and enhance their ability to choose freely those activities and lifestyles they have reason to value.

Until recently (Nussbaum, 2011, p.197) there have been two pertinent dynamics at work for Sen in evaluating capabilities: a person's agency and their well-being. These correspond with social perspectives on mental distress which critique the state's role in constraining freedoms ostensibly to maintain wellbeing (Wallcraft, 2010) and are pertinent to this study. For Sen, agency and wellbeing may in the real world complement or contradict one another (e.g. taking risks may compromise life) and each need consideration in terms of both the freedom to achieve them (capability), and their actual achievement, or functioning (1993, p.35; also discussed in Sen, 1985; 1992). This leads Sen to four concepts: well-being achievement, agency achievement, well-being freedom and agency freedom. Sen concretises the way in which these dimensions may help, for example, the state to decide which type of deprivation requires state support; for example providing for a person's well-being (e.g. support to overcome hunger or illness) rather than their agency; or to well-being freedom rather than well-being achievement (e.g. offering a person 'real opportunities' (1993, p.39 n.23) to overcome hunger whilst not insisting that the person takes up that offer).

Davidson et al (2009, p.40) contend that whilst mental distress may be an 'obstacle' to achieving a desired life or 'may even deprive the person of life altogether', mental distress does not:

...fundamentally alter the basic nature of human beings, which is that of being self-determined agents, free to choose and pursue the kind of life they as individuals value.

A capabilities analysis would evaluate the degree to which community support, treatment and rehabilitation 'support people in their own choices and pursuits' rather than 'act as prerequisites or substitutes for the lives they desire to lead' (2009, p.41). They hint at the times when mental distress takes the form of suicidal feelings, an extreme conflict between wellbeing and agency. However, they avoid full engagement with the contradiction of state interventions to preserve the functioning of life against a person's will, agency being overridden due to a wider dominant normative understanding of wellbeing.

This is taken further in an earlier suggestion of Sen (1985, p.204) in a rare direct reference to mental distress in which he noted in relation to agency:

When the requirement of careful assessment cannot be fulfilled (e.g., in the case of young children, or with persons mentally ill in ways that rule out such assessment), the agency aspect will be, obviously, less important. This does not indicate that the demands of the agency aspect for such a person would have to be assessed by others on his or her behalf, but only that no such demands would then be made. This would not ... compromise the importance of their well-being aspect. Indeed in the absence of the relevance of their agency aspect, it is their well-being achievement that would uniquely command attention.

This suggests that for children and people with mental distress, agency may be disregarded as not relevant and only wellbeing matters; the functioning must be assured. Nussbaum pursues this issue in relation to people with cognitive impairments (e.g. 2011, p.24), arguing that capabilities may need to be pursued by a surrogate, and that agency would only be overridden in specific cases, for example for 'a person in a permanent vegetative condition or an anencephalic person' (2011, p.24). Whilst the concept of 'surrogates' parallels in some ways the roles of advocates, nearest relatives and advance statements in terms of mental distress, both Sen and Nussbaum avoid the social-political complexities of mental distress highlighted by the sociology, staying with more abstract (Sen) or less potentially conflicted social groups (Nussbaum). The 'cut-off points' between agency and wellbeing - or freely expressing capabilities versus securing functionings - may be especially fluid and complex for subjective mental distress due to its fluctuations and cultural relativity. Whilst the upholding of functionings is the dominant concern for Sen and Nussbaum, in the context of mental distress this repeats the history of coercion and removal of agency related to judgments of lack of 'insight' which plague questions of social justice for people with mental distress. Issues of definitional power in the mental health system, allied to the legislative, coercive role of the state are hardly new, but neither Sen nor Nussbaum address these, and even Davidson et al tiptoe around it.

Whilst Nussbaum has argued that the agency/wellbeing distinction is unnecessary, as long as wellbeing is 'sufficiently refined' (2011, p.201), in this context she may be premature in her dismissal of this distinction. Sen's

distinction continues to be analytically informative for evaluation of the social justice of people with mental distress.

### **3.2.8 Participation**

The capabilities approach emphasizes that groups facing oppression must themselves be actively involved in judging what substantive and valued capabilities are. One group cannot be liberated by another and ‘‘choosing’ itself can be seen as a valuable functioning’ (Sen 1999, p.76). As noted earlier, this also reflects principles of both the disability and mental health user movements. However, people with mental distress haven’t yet significantly participated in interpreting substantive and valued activities.

### **3.2.9 The domains and thresholds concept**

Distinctively from Sen, Nussbaum (2006, p.71) has argued for a:

... threshold level of each capability, beneath which it is held that truly human functioning is not available to citizens; the social goal should be understood in terms of getting citizens above this capability threshold.

Thus (2006, p.75) she has developed a philosophically derived:

... attempt to justify a list of ten capabilities as central requirements of a life with dignity... all are held to be a part of a minimum account of social justice: a society that does not guarantee these to all its citizens, at some appropriate threshold level, falls short of being a fully just society.

Nussbaum advocates that the central capabilities, originating in Nussbaum (2000), are ‘the ones that a minimally just society will endeavour to nurture and support’ (2011, p.28). They are therefore not trade-offs: ‘all need to be secured and protected’ (2011, p.35), but all are not equal in a simple way, for example for Nussbaum the capabilities of affiliation and practical reason play an ‘architectonic role: they organize and pervade the others’ (2011, p.39).

She has consistently argued that the list needs to be further specified within each society through public discussion (e.g. 2006, p.75), echoing Sen’s call for public reasoning and participation in defining capabilities.

Her list of central capabilities entails general goals, which (2006, pp.75-76) are:

not intended to provide a complete account of social justice. It says nothing, for example, about how justice would treat inequalities above the threshold ... It is an account of minimum core social entitlements...

Nussbaum indicates here that her account does not address inequality, provided all citizens are above the threshold level. However, this appears to conflict, for example, with her normative claim that ‘we should seek principles of justice that accord full justice and equality to people with disabilities’ (2006, p.63). The question of equality is an issue that sociological evidence, led by Wilkinson and Pickett (2009), suggests cannot simply be ignored in order to achieve social justice, including in terms of reducing incidence of mental distress.

The sense from Nussbaum is that threshold achievement is a minimal account of social justice or minimum dignity which, if attained, offers the possibility of ‘truly human functioning’ or the ability to choose substantive alternatives or capabilities. How secure a definition this is in terms of promoting and securing social justice for people has been critiqued by Venkatapuram (2011, pp.118-119 and 144-155), by Wolff and deShalit (2007) and by Riddle (2010; 2014). Similarly, Nussbaum tends towards understanding her central capabilities as capability thresholds, rather than functioning thresholds (e.g. 2011, p.36), ‘because of the high value [Sen and I] ascribe to choice’ (2011, p.26), critiqued by Wolff and deShalit (2013).

In 2006 Nussbaum listed her ‘current version’ of ten ‘Central Human Capabilities’, which she expected to be modified in the light of public discussion (2006, p.76), as (headings): 1. Life; 2. Bodily Health; 3. Bodily Integrity; 4. Senses, Imagination, and Thought; 5. Emotions; 6. Practical Reason; 7. Affiliation; 8. Other Species; 9. Play; 10. Control over One’s Environment (Political and Material). Within these headings, Nussbaum specified such capabilities as (7) ‘nondiscrimination on the basis of race, sex, sexual orientation, ethnicity, caste, religion, national origin’ without reference to nondiscrimination on the basis of impairment or mental health status (2006, p.77). Other capabilities incorporated within Nussbaum’s domain headings included (1) ‘Being able to live to the end of a human life of normal length; not dying prematurely, or before one’s life is so reduced as to not be worth living’;



(2) Being able to have good health (2006, pp.76-77). These incorporate normative judgments about a life that is worth living, and definitions of good health and dignity, critiqued by Venkatapuram's social definition of health justice or social justice (2011, p.20), but which merit participation by people with mental distress.

Burchardt and Vizard (2011) and Wolff and deShalit (2007) have developed research approaches based on Nussbaum's list of basic human capabilities, balanced with a 'bottom-up' process of identification of subjectively valued capabilities of groups experiencing social injustice. Their work is discussed in the methodology (chapter four), but some observations from their studies at this stage inform interpretation of the domains and thresholds concepts.

In their study, Burchardt and Vizard (2011) used the concept of 'flourishing' to convey the intention of the thresholds that a person must surpass. Whilst this might be interpreted as a generous interpretation of Nussbaum's thresholds, it is resonant with the concept of dignity, core to Nussbaum in particular (e.g. 2011), but demonstrates the ambiguity in the meaning of the thresholds, noted by Venkatapuram (2011, p.243 n.11). This abstruseness was also discussed by Wolff and deShalit (2007, pp.37-40) and by their participants who distinguished between an acceptable life and a good life (2007, p.51), further reinforcing this opacity from a lay perspective.

For Wolff and deShalit, 'Being able to express feelings for others' emerged as important to thriving, underplayed in the domains by Nussbaum despite her work on the ethics of care (2007, p.45). This provided them with a wider critique of Nussbaum's domains as being focused on 'the liberal, autonomous individual who cares for her entitlements rather than the active member of a community who participates in social and political activities' (2007, p.45). This is a harsh criticism of Nussbaum's domains which specifically included dimensions of affiliation and participation. However, she does risk this interpretation, a criticism which is linked to the external critiques of capabilities by Dean (2009) and Harvey (2014) of being at risk of capture by existing structures and dominant social norms.

Finally, Wolff and deShalit also found that security of functionings - not only capabilities - over time was important to flourishing, contradicting the ultimate focus of Sen and Nussbaum on choice (Nussbaum, 2011, p.26). Nussbaum (2011) responded to their work, Wolff and deShalit countering in turn (2013), the debate over functionings or capabilities being the appropriate measure to secure 'capability security' or the basis of social justice, continuing.

### 3.2.10 Summary

Figure 2 is a schematic diagram which for analytical purposes provides a sense of the normative intent of the capabilities approach, its aim to widen functionings and capabilities for disadvantaged people and groups, shifting them from left to right. The capabilities approach argues that personal, social and structural Conversion Factors need to work together to enable a person to go from left to right, expanding their capabilities and functionings. But the diagram shows that this will be influenced by the resources that the individual holds, adaptive preferences, diversity/heterogeneity, the agency/wellbeing tension and the social, cultural and economic environment.

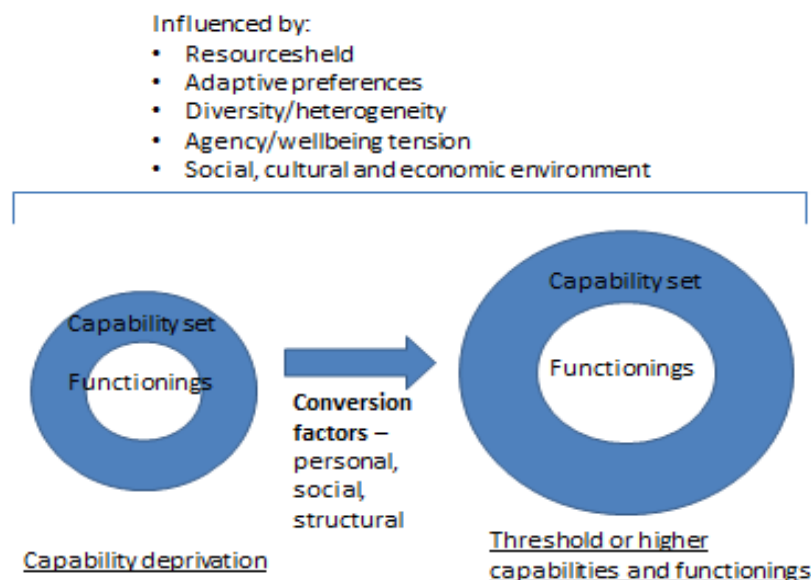


Figure 2. A capabilities model of social justice: widening the capability set for disadvantaged groups and individuals, enabling conversion into socially valued functionings.

Agency is integral to a capabilities analysis, logically leading to a concern for diversity and freedom. But capabilities does not keep agency in a vacuum. Capabilities is about the empirical analysis of how agency operates in a social context to determine freedom to achieve socially valued goals and thus social justice. The somewhat neglected agency/wellbeing tension in the capabilities approach brings in the notion that people may subjectively act in ways which undermine their objective wellbeing, a pertinent consideration for experiences of mental distress and, for example suicide. Although capabilities brings in the concept of adaptive preferences this is a limited way of understanding social injustice. An adapted version of Conversion Factors brings in the influence of underlying structures to explanation of what people are actually able to do and be, which also has the potential to more fully explain how social justice outcomes are structured for people, including through social determinants. The domains framework offers a more objective means of evaluating social justice outcomes. Incorporating sociological dimensions into the capabilities approach extends the possibilities for explaining social justice experiences as defined by Venkatapuram.

Subjective mental distress can be understood as a personal Conversion Factor, disrupting agency (Tew, 2011), but experienced in a context of social and structural Conversion Factors such as the shaping and application of laws related to treatment for mental distress, the social construction of treatment options, the role of the pharmaceutical industry and the state in shaping treatment choices, and the impact of dominant social norms on social behaviour. The emphasis in the survivor literature on personal experience is integrated into capabilities through the participation principle. The concepts of social construction, social norms and social oppression that influence social perspectives of mental distress may be empirically analysed through capabilities by a focus on how the agency of people with mental distress is structured by the external world, which has norms about social behaviour and may construct 'mental illness', and, contrarily, how people may have their heterogeneity respected in this context, using functionings and capabilities to interpret what people are actually able to do and be.

### 3.3 Sociological critique of the capabilities approach

Holmwood (2013) highlights the peculiar 'immunity' of sociology to the capabilities approach, which has been applied and critiqued in allied subjects such as social policy (2013, p.13), attributing this to both the lack of engagement with sociology from capabilities scholars, and due to mainstream sociology being dominated by a focus on critique of capitalism and the welfare state (2013, pp.8-11). Where engagement has happened, Holmwood identifies the sociological critiques of capabilities: namely the avoidance of analysis of structural explanation for individual vulnerability (2013, p.9) and capabilities' ambivalence about inequality at the expense of a focus on choice (Holmwood, 2013, p.11; also Walby, 2012). Holmwood argues that these critiques overlook capabilities' concern for outcomes, and that sociology could benefit from capabilities use of 'normative language to address inequalities' in the context of the necessary relativism of diversity (2013, p.11). Whilst he suggests that Sen's critique of distribution within the market economy is in sympathy with sociology's critique of the welfare state, this is challenged by Harvey (2014) below.

Holmwood suggested that capabilities and sociology were in fact compatible in several dimensions, including: capabilities' normative interest in the relationship between outcomes, choice and inequality (2013, p.11); concern for inequalities beyond the distribution of commodities (2013, p.10 and 11); interest in absolute and relative questions of distribution (2013, p.10); questioning of institutional arrangements and their role in aiding or hindering human flourishing (2013, p.6); and critique of the abstraction of the normative from the empirical (2013, p.5). He suggested that Burawoy's recasting of sociology as a form of public reason (Holmwood, 2013, p.2) was in harmony with capabilities' focus on the self in society and on public deliberation.

For Holmwood, sociology may hold a significant role in overcoming the tendency of capabilities to overgeneralise subtle dimensions of the lives of identity groups (2013, pp.6-7). This is a concern of the current study - not only in terms of critiquing generalisation of the lives of people with mental distress, but in taking identity dimensions beyond mental distress seriously: humans as complex social beings. But contra to Holmwood, as the last chapter demonstrated, the sociology

of mental distress could also attribute ‘master status’ assumptions to mental distress, also at risk of overgeneralising.

Due to his focus on mainstream sociology, Holmwood leaves aside discrete social science that has engaged more strongly with capabilities. Disability studies (e.g. Burchardt, 2004; Mitra, 2006; Dubois and Trani, 2009) has reconceptualised disability as a capability deprivation, applying capabilities to focus on inequality both within and beyond resource distribution, specifying the role of institutional arrangements in shaping social justice for disabled people, the very compatibilities highlighted by Holmwood (2013, p.11). Zimmerman (2006) had also provided an earlier analysis of the possibilities for sociology in the context of capabilities in terms of qualitative methodologies, explored in the next chapter.

Other disciplines at the edges of sociology, such as philosophy, social policy and geography have also provided engaged critiques. Sayer prefigured Holmwood’s concern (2011, p.238) explaining that whilst capabilities analysis gets beyond simple resource measures in revealing *what* is and is not being met for social groups, social sciences helps to explain *why* this is the case. He identified synergies between capabilities and critical social science in terms of a normative social science needing to evaluate ‘avoidable suffering and forms of well-being’ (2009, p.769), capabilities analysis bringing together facts and values from which practical, political conclusions could be drawn, a point also endorsed by Zimmerman (2006, p.481).

Sayer has proposed that a ‘naïve view’ (2011, p.238) of the role of the state tends to be taken by capabilities analyses due to a lack of application of social scientific knowledge about the actual role of states, exemplified (2012, p.5) in the Equalities Review, which ‘ignores structural external conditions and treats inequality as an accidental residual feature of British society... Its understanding of the structural causes of inequality is lamentable’. However (2012, p.4):

...these are objections not to CA as a normative theory ... [I]t is not difficult to combine CA with an understanding of power, class and other axes of domination in ways that support radical conclusions...

By arguing for the need for a social scientific explanation of structural external constraints that shape the achievement of capabilities, Sayer suggests an analytical synergy between these two fields in understanding social justice for disadvantaged groups such as people with mental distress.

As Dean (2009, p.261) has noted, capitalism is ‘the elephant in the room’ in capabilities literature. As noted above, Harvey (2014, p.210) has similarly critiqued Sen for his faith in the market system:

[Sen’s] core belief, for which he can provide no definitive evidence, lies in the idea that the market system, properly regulated and managed, is a just and efficient way of fulfilling human wants and needs, and that it can produce freedom from want in a free way.

Harvey argues that the capabilities’ notion of freedom is actually a structured freedom; a fuller notion of freedom can be achieved by incorporating critique of capitalist-based social relations into the analysis. For example, for people with mental distress the power of the pharmaceutical industry as complicit in the social construction of diagnosis and modes of treatment (Busfield, 2011) is relevant to a critical analysis of freedom and social justice outcomes.

Thinking about capabilities sociologically can create an expansive and critical model of capabilities; a fuller explanation of social justice outcomes; and incorporates underlying structural forces that shape the way the world tends to operate, leading to non-conscious hierarchies of socially valued people and practices. Working with the sociological theory of critical realism, as suggested in the last chapter, may allow the layer of the real - causal mechanisms independent of our perception (Bhaskar, 1978) - to be incorporated into the analysis.

### **3.4 The capabilities approach as an ethically-informed model to interpret lived experience of mental distress**

So the capabilities approach has the potential to shed light on the social justice of people with mental distress in a way which is not restricted to use of services or compliance with treatment regimens because it focuses on whether all people have the freedom to live a valued life. Added sociological explanation can expand and deepen the analysis. Wallcraft (2010), Hopper (2007) and Davidson

et al (2009) have argued that applying the capabilities approach to understand mental distress from a social perspective using qualitative methods is overdue and may hold conceptual, analytical and theoretical advantages.

Wallcraft (2010), another researcher with experience as a mental health service user, has suggested that the capabilities approach holds potential because of its emphasis on the whole person and focus on flourishing, and on practices and structures, such as aspects of mental health treatment and social stigma that may restrict social justice. She suggested that by analysing the power of diagnosis and treatment to create capability deprivation the capabilities approach may reconfigure social models, arguing that personal experience as evidence is needed both to explore how lives may have been restricted through social and medical responses to mental distress and to explore the actual hopes, needs and wishes of people with mental distress for a full life.

Davidson et al (2009) have also posited that capabilities can be used to critique recovery, adding, like Wallcraft (2010) that the interest in human freedoms, diversity and self-determination inherent in capabilities can take analysis beyond institutional provision into issues of social justice of interest to the survivor movement.

Alexander and Hopper (2007) suggested that Sen's framework can support analysis of the experiences of people with mental distress. Their regard for literature that has aimed to apply capabilities to disability (e.g. Burchardt, 2004; Mitra, 2006) keeps their argument grounded in the diversity of disabled peoples' lives in a way that Sen and Nussbaum, precisely due to their lack of recognition of disability studies literature, were unable to achieve. However, in their U.S paper the repressive elements of the state in relation to people with mental distress, ontological questions about the social construction of mental distress, and normative questions of difference in values are left underanalysed.

In a closely related paper, Hopper (2007) has suggested that capabilities might offer a more complete analysis of agency/structure relations and personal experience that interact to create quality of life for people with mental distress, and could provide possibilities for social action by revealing injustice. He argued that, in comparison with the individualised notion of recovery, a capabilities

perspective highlights structure - 'vital contextual features - the enabling resources, rules and connections that make prized prospects like a decent job feasible' (2007, p.871). This chapter has shown that sociological concepts make this prospect feasible.

Hopper suggested that people with mental distress offer a challenge to the capabilities approach itself due to what he calls the 'transformative power of psychosis' (2007, p.876). Their experiences may question normative assumptions in capabilities of what constitutes quality of life. The emphasis in capabilities on the value of 'freedom to lead different types of life' (Sen, 1993, p.33) may be challenged by lived experiences of confinement, surveillance and discrimination (2007, p.876). These notions are compatible with the concerns of survivor-influenced perspectives with the oppressive experience of the psychiatric system, and by counter-normative behaviours by people with mental distress which may raise questions about dignity and freedom, fundamental to the philosophy of capabilities. Hopper questions capabilities' narrow interpretation of dignity, from Adam Smith's 'linen shirt' principle, that 'the esteem of others is essential to achieving self-respect' (2007, p.877). This measure of 'esteem' may be upheld in Scotland, but at the price of autonomy, for example by imposing a Compulsory Treatment Order involving medicalisation, social constructivism and narrow dominant norms. Hopper counter-argues (2007, p.878) for:

...freedom to put that security at risk (subjecting oneself, say, to ridicule or pity)... Symptom management is highly valued and avoiding stress is good coping strategy. But electing to try paid work, at risk of upsetting proven routine and established habits, may make sense if potential gains are thought sufficient. (Service-users sometimes call this being accorded "the dignity of risk.")

So people with mental distress may challenge implied capabilities paternalism. Hopper's use of the capabilities approach as critique works expansively as does Pilgrim and Bentall's (1999) use of critical realism as critique in the context of depression, or Bhaskar and Danermark's (2006) critical realist critique of the reductionism of disability analysis.

Although these authors argue that capabilities can provide these critiques, there is little research applying capabilities to lived experience of mental distress.



Several UK studies have aimed to apply capabilities as a method for evaluating mental health services (Simon, 2011; Lorgelly et al, 2008). Only Tang (PhD, 2014) has critically applied the capabilities approach to lived experience of people that use psychiatric services in the UK, with a focus on recovery in the Chinese community. Several small-scale U.S studies have also indicated critical potential (Ware et al, 2007, 2008; Lewis et al, 2012) as described in the next chapter.

### **3.5 Conclusion: the contribution of capabilities to understandings of mental distress**

Ontologically the capabilities approach draws on theories of justice rather than on biomedical or sociological theory. Epistemologically it is interested in the quality of the whole life, not just life in relation to the psychiatric system, so has the potential to be a least reductionist framework, compatible with critical realist ontology. Conceptually, it offers the analytical possibility of considering not only how life is, but how life could be, through functionings and capabilities, and to evaluate this using qualitative methods to pursue dimensions of life that seek to explain the breadth of social justice experiences of people with mental distress. This opens the possibility, as argued by Trani et al (2011), of research to develop ‘expanded capabilities’, capabilities that are of importance to this social group that may only be discovered through direct study. The analysis may in turn inform the capabilities approach itself.

So, a capabilities analysis has potential for ‘attempting to reconceptualise mental distress within a social framework’, to paraphrase Beresford (2010, p.57). However, sociological and other critiques ask challenging questions of capabilities. Whilst Nussbaum’s domains suggest a duty on the state to at least provide for basic needs to a capabilities-based threshold, critiques ask whether this is sufficient for thriving (Wolff and deShalit, 2007; Venkatapuram, 2011) or appropriate for dignity (Hopper, 2007). They press the issue of the significance of social determinants in social justice outcomes (Venkatapuram, 2011). They ask about the impact of inequality on the wellbeing of all (Wilkinson and Pickett, 2009). They highlight the role of the state in upholding unjust social relations compatible with the market system, and highlight the void in understanding the layer of the ‘real’ (Bhaskar, 1978) beyond this (Harvey, 2014; Sayer, 2012). The

relational, self-in-society character of capabilities makes it compatible with critical realism, meaning that the analysis of what people can do and be may locate explanation in the underlying structures as well as in what is empirically observed (Fisher, 2009). Dubois and Trani (2009) argue that the capabilities approach is 'able to encompass all the previous models' in understanding the complexity of disability (2009, p.197); incorporating sociological analysis, this may be upheld for social understandings of mental distress, with Conversion Factors being applied as an analytical 'bridge' to operationalise the tension between agency and structure as they influence social justice outcomes.

The development of what might be termed a critical capabilities model of mental distress, adding sociological theory to a capabilities conceptualisation of lived experiences of mental distress, needs to incorporate the normative approach of capabilities to conceptualise and reduce social injustice; a sociological analysis of the world as experienced by people with mental distress; and an understanding of the importance for explanation of underlying structures to social justice. This is returned to in the discussion and conclusion, chapter nine.

As seen in the last chapter, several studies have drawn out qualitative data to provide a fuller picture of the lives of people with mental distress. These have empirically explored the lives of people with mental distress, critically accommodating the subjective reality of mental distress whilst critiquing the psychiatric system and analysing agency/structure relations, in order to critique substantive and formal theory (e.g. Barham and Hayward, 1991; Parr, 2008). This type of in-depth study has not yet been conducted using a capabilities framework for analysis or using explicit critical realist ontology, the contribution of this study. The literature and empirical evidence suggests that this is of value for both understanding the quality of life of people with mental distress, and for testing the limits of the capabilities approach. This thesis can thus be posited both as a qualitative exploration of the lived experience of mental distress using concepts from the capabilities approach, and as an exploration of the capabilities approach through a qualitative study of mental distress.

## **4 Methodology**

### **4.1 Introduction**

The introduction chapter explained the need for a piece of research to reconceptualise the lived experiences of mental distress through a social framework. The last two chapters have explained research traditions in the sociology of mental distress and the perspective taken by the capabilities approach and has elucidated that these may be combined analytically in a least reductive manner through a critical realist ontology. This chapter first explains how the study is informed by the theoretical underpinnings of the research questions, the necessarily interpretivist framework used by the study (Creswell, 2013, ch.2), and how this is compatible with both capabilities and a critical realist ontology. It then sets out the qualitative research principles followed by the study and how the research design is informed by capabilities literature. Then applied research design, fieldwork and analytical choices are explained, including consideration of quality in qualitative research. Throughout, the account takes a reflexive position, consistent with the underpinning epistemology of the study, namely that the researcher is also embedded in underlying structures and discourses whilst holding degrees of agency.

### **4.2 The epistemological approach to the study**

A critical realist approach accepts that subjectivity is important but is not 'value free'; theories of reality are socially constructed. This demands a research design that accesses discourses, perceptions and meanings, but which strives for objectivity within this, consistent with the critical realist position that there is a material base beyond the discourse (Rogers and Pilgrim, 2010, pp. 16-19). Therefore a weak social constructivist position (Rogers and Pilgrim, 2010, pp. 15-16; Creswell, 2013, pp. 24-25; Blaikie, 2010, pp. 170-171) is required to critique lay epistemology, so not taking pre-existing categories, language, models and theories at face value whilst understanding at the same time that in the interplay between power, language and/or social actions a set of regularities in social life may be interpreted through structuralist theory, brought together in a unified and normative analysis. The data emerging through the study is therefore contextualised, not taken as 'truth', combining, as Rapley (2003) noted of

Alderson's (2001) 'exemplary' qualitative analysis of quality of life for young people with Down Syndrome (2003, p.106), the emic and the etic, the views of participants with academic theories or models, in order to develop persuasive argument.

By following Braun and Clarke's conceptualisation of thematic analysis using a constructivist epistemology (2006, p.85) and an interpretative approach to analysis (2006, p.84) the present study draws out 'underlying ideas, assumptions and conceptualizations - and ideologies' (2006, p.84, their emphasis) that bring a realist interpretation, producing a least reductionist approach to the capabilities model.

### **4.3 Positionality and qualitative mental health research**

This study problematises the notions of 'insider' and 'outsider' in terms of relations to mental distress. As a person with previous experience of mental distress, including in the form of a diagnosis of mild depression and anxiety, I am an insider to the general experience of managing the personal and social impact of mental distress, knowing how it can feel for subjective emotions to act autonomously from experiences, and an insider in relation to the social management of a diagnosis/label. I am an outsider in terms of hospitalisation, having a psychiatrist, in terms of living with a strong experience of mental distress, and in terms of the diagnosis/label of schizophrenia, bipolar disorder or their variants. However, a shared diagnosis, or common experience of hospitalisation or treatment also does not constitute a directly comparable 'insider' experience. As this study confirms, diagnoses are unreliable, all people are uniquely socially situated and expressions of distress are infinite. In terms of analysis, the factors by which to judge qualitative studies are wider than the personal experience of the researcher (Tew et al, 2006) and critical realism asserts there is always an interpretive element in making sense of independent reality, rejecting the notion that knowledge of reality can be 'objective', a position also held by capabilities (Tao, 2014, p.72). Thus within a critical realist ontology, researchers are not simply insiders/outsideers or indeed survivors/service users or the opposite, as can be implied in 'survivor research' paradigms (e.g. Sweeney, 2009; Beresford, 2009, pp. 51-52). Instead an interpretive study recognises that researchers are embedded in social structures

and discourses, whilst able to exercise degrees of agency, and it is the reflexivity demonstrated towards these issues which contributes to qualitative rigour (Spencer et al, 2003, p.7).

## 4.4 The strategic and methodological approach

As noted in chapter two, the most nuanced studies into the lived experience of people with mental distress critically accept subjective experiences of mental distress whilst developing critiques of the psychiatric system and analysing agency/structure relations, in order to develop critiques of substantive and formal theory (e.g. Barham and Hayward, 1991; Parr, 2008). These types of study are compatible with social perspectives on mental distress, which also advocate the engagement of personal experience with structural barriers (e.g. Beresford, 2004, p.218). Their credibility and fitness for purpose (Spencer et al, 2003) comes from the rigour of analysis and transparency of reporting of a sample of subjective experiences.

As also seen in chapter two, large-scale studies suggest that people with mental distress tend to experience social injustice (Scottish Executive, 2004; Allen et al, 2014). In sociology, attention has been paid to macro-level social determinants (e.g. Allen, 2014), and less commonly to peoples' subjective understandings and experiences (The Living Project Steering Group, 2004). However, Tew et al (2006, p.12) have noted:

Now that the majority of mental health care is delivered in community, rather than hospital settings, the need for research to recognise the complex interplay of social, psychological, economic, political and environmental factors on an individual's mental well-being is ever more vital.

Similarly, Parr et al (2004, p.401) in a study drawing out the complex and relational subjective aspects of living with mental distress, argued that there was a need to explore the:

...experiential processes... leading particular individuals and groupings to be excluded from the norms of everyday social life, activity and 'participation'

However, evidence from disability studies suggests that in-depth qualitative research into quality of life for specific groups may elicit counter-intuitive findings (Albrecht and Devlieger, 1999; Alderson, 2001), revealing ways in which quality of life may be subjectively high. One clear advantage of in-depth qualitative studies is that individual nuances and micro-changes in understanding and experience are highlighted, not 'banded out', in the context of mental distress revealing otherwise marginalised lay interpretations (Rose, 2007).

In a qualitative study with socially excluded people, Emmel and Hughes (2009) exposed heterogeneous relational practices that disrupt formal statistical categorisations of people, revealing in a different context the type of counter-intuitive findings found by Albrecht and Devlieger (1999) and Alderson (2001). They proposed that using comparative cases provides more opportunity for theoretical development, to explore (2009, p.329):

multiple and varying relationships that happen in any open social system and to triangulate these in sharpening theoretical development...  
(facilitating) a critical engagement with sociological constitution of boundaries of the social world under investigation

Through recruiting participants in comparable social positions and comparing networks they demonstrated how exclusion may be reinforced for some individuals, not others. Although possessing common attributes (2009, p.323):

actors may respond to and interact with structures in very different ways... These intentional acts (Bhaskar 1979) may lead to an elaboration of structures by social actors or their reproduction (Archer 1998).

Through taking a critical realist perspective they were able to theorise on power and powerlessness and the roles of structure and agency, with people seen as holding emergent properties. Through comparison, they suggested that theory may be refined and critical realist generative causal mechanisms identified 'across cases, or, as importantly, be particular to one case' (2009, p.325). The present study may similarly recruit participants with comparable networks, revealing, as Emmel and Hughes achieve, factors which reproduce exclusion for some individuals being rescripted by others, so illuminating dissonance or conjunction across the sample.

Tew et al (2006, p.vi, summarised below, their emphases) have proposed five principles as a value base for mental health research that aims to respect the values, aspirations and concerns of service users:

- **Partnership** - meaningfully involving relevant stakeholders, such as service users, in key aspects of the research process.
- **Standpoints and distance** - combining the experientially based knowledge of service users with rigorous analysis, so that an authoritative picture can emerge.
- **Holism not reductionism** - looking at a person's experience as part of their wider social context, leading to a focus on social change as well as individual recovery.
- **Recognition of social diversity** - acknowledging the impact of social divisions on people's experience, and being cautious about applying research findings from one social group to another.
- **Emancipatory purpose** - using research to produce evidence and theory that can enable service users to have a greater **awareness** of their situation so that they can make informed decisions and choices; have more **control** over the direction of their lives; **participate** more in social, economic and political life; enable them, in conjunction with practitioners and members of the wider community, to **challenge** stigma, injustice and social exclusion.

The exploratory and normative character of this study implies that a values-based approach is necessary, achieved through methods that draw on Tew et al's principles. The capabilities approach also has guiding principles of participation and normativity, providing a second driver for this decision. Critical discussion of the extent to which this study attained these principles can be found below.

Goerne observed that Zimmerman had identified the need for more qualitative research using the capabilities approach in the sociological context, 'a suggestion which yet has to be taken up' (2010, p.16), a gap also acknowledged

by Nussbaum in her keynote address to the Human Development and Capabilities Association conference (Managua, September 2013), attended by this researcher. Zimmerman (2006, p.481) argued that whilst qualitative inquiries were susceptible to the criticism of restricted generalisation, they may:

... allow one to establish typologies, to point out salient features and relevant elements providing a basis for the working out of statistical surveys and indicators... Skipping the qualitative dimension would mean a serious loss in assessing the complexity of social facts, their changing and interacting character, but also - and this is an important point in respect to capabilities - people's ethical assumptions and expectations.

The present study attempts this empirically, presenting and analysing subjective complexities to reveal underpinning ethical assumptions, whilst reversing Zimmerman's logic - the macro-level data on social injustice (chapter two) driving the need to explore the complexity underneath these figures, using an ethical framework, in this case the capabilities approach.

## **4.5 The application of the capabilities approach in qualitative research**

As seen in chapter three, capabilities is a measure of social justice and wellbeing that incorporates agency and diversity and which aims to understand what people are actually able to be and do, rather than to measure ciphers for this. This suggests that capabilities would naturally lend itself to primary research.

Sen has noted that measuring a person's chosen functioning is easier than measuring the capabilities available to them, due primarily to data availability (e.g. 1992, pp.52-53). He has emphasised that this logic does not preclude the need to also be mindful of the importance of the 'extent of freedom to choose between different functioning bundles' (1992, p.53). So, a methodological question is posed: how is it possible to explore the capabilities of a sample of people with experience of mental distress in order to reveal qualitatively valid data at the levels of both functionings and capabilities?

Sen opens a useful line of argument about choices in evaluation of quality of life of relevance to people with mental distress (1992, p.20):



The relative advantages and disadvantages that people have, compared with each other, can be judged in terms of many different variables, e.g. their respective incomes, wealths, utilities, resources, liberties, rights, quality of life, and so on. The plurality of variables on which we can possibly focus ... to evaluate interpersonal inequality makes it necessary to face ... a hard decision regarding the perspective to be adopted. This problem of the choice of the 'evaluative space' ... is crucial to analysing inequality.

In considering the 'evaluative space' for mental distress, variables such as liberties and rights are of salience in the literature. But other variables may be of subjective salience. A least reductive, critical realist analysis requires accounting for both.

In his earlier work, Sen noted that researching the weighting of different functionings is a complex and inexact matter, in which 'clarity of theory has to be combined with the practical need to make do with whatever information we can feasibly obtain for our empirical analyses' (1987, p.32). For Zimmerman, capabilities has lacked a theory of society and a methodology of enquiry, and, without these, capabilities 'cannot be sociologically implemented' (2006, p.469). This suggests an opportunity for sociology to enable analysis of the personal within the social-structural.

Zimmerman suggested that combining interviews with ethnographic observations would allow for exploration of the inobservable and observable qualities of capabilities and functionings, creating a situated assessment of opportunities, recognising that people may value options in some situations but not in others, changing over time (2006, p.479), understanding empirical life as ongoing (2006, p.482 n.13) and pursuing an integrated understanding of the individual. She argued that the temporal dimension had been 'neglected' by capabilities (2006, p.469). Zimmerman is still in part correct (pace Alkire, 2007, for example); consideration of past and future seems implicit to capabilities evaluations, as also suggested by Wolff and deShalit (2007) and Venkatapuram (2011) in their concern for security of thresholds.

Alexander and Hopper (2007) have argued that applying the capabilities approach to qualitative studies of lived experiences of mental distress '...is technically demanding and wide-ranging work, and no synthesis is at hand'

(2007, p.10). Two types of relevant empirical research are emerging. First, a set of inductive primary studies from the U.S, located within symbolic interactionist ontology and using grounded theory in the context of the recovery model in order to qualitatively research and relationally analyse the capabilities experiences of people with mental distress. Second, an approach combining inductive and deductive methods with disadvantaged groups, led by Burchardt and Vizard (2011) and Wolff and deShalit (2007), as seen in the last chapter, and incorporating the normative, more objective framework of Nussbaum's domains approach into primary research.

In the U.S studies, Ware et al (2007, 2008) and Lewis et al (2012) used a subjectivist epistemology, interpretivist theoretical perspective and methodologies from the ethnographic and grounded theory school. They each explored the experiences of a small group of people formerly hospitalised due to mental distress, and who used community care. Ware et al (2007) focused on understanding social integration as a dimension of quality of life for a purposive sample of users of social programmes; Ware et al (2008) re-analysed the same data to explore agency as an aspect of social integration. Lewis et al (2012) conducted an ethnography of a user-led day centre to explore the type of connectedness that this type of project engenders.

The three studies explore the social processes that make up one concept (agency or connectedness), rather than measuring functionings and capabilities across domains, as in Nussbaum's (2006) framework. Ware et al (2008) was notably limited by a focus on life within community care services, rather than other areas of life for people with mental distress, and therefore loses an overview of the whole, emergent life, which a capabilities analysis has the potential to achieve. In common, these studies are weak in their use of social theory to interpret findings, and are constrained in their ability to analyse social actions across laminates due to a lack of critical realist ontology. In contrast to the U.K survivor-influenced tradition, they do not critically analyse the role of psychiatric services and the repressive elements of the state. Whilst these choices constrained them, the use of capabilities as a conceptual framework to define social integration (Ware et al, 2007), to inform their data analysis (Ware et al, 2008) and to frame their theory, research question and analysis (Lewis et al, 2012) allowed the studies to re-frame assumptions about social integration

for people with mental distress (Ware et al, 2007), develop new concepts to define integration (Ware et al, 2008) and consider how reciprocal and accountable relationships may reconceptualise connectedness (Lewis et al, 2012). These studies therefore suggest 'expanded capabilities' (Trani et al, 2011) and the possibility of theoretical development.

Burchardt and Vizard (2011) and Wolff and deShalit (2007) have demonstrated that the capabilities approach can be applied by bringing together the subjective and more objective dimensions of social justice for disadvantaged groups beyond the constraints of service systems.

Burchardt and Vizard (2011) invited a sample of people in Britain at risk of discrimination and disadvantage, but not specifically including people with mental distress, to 'discuss and reflect upon what is needed for a person to flourish in Britain today and to lead a life that they value and would choose' (2011, p.104). Their research exercise, conducted as part of the development of Britain's Equality Measurement Framework, first asked the sample to spontaneously draw up domains that were important for a person in Britain to flourish, and, in a second stage, suggested a list of domains based on a selection of human rights instruments. They used a 'trumping' rule so that human rights fundamentals could not be overturned by their sample. This led to the following list of domains, each containing a series of examples: life; physical security; health; knowledge, understanding and reasoning; standard of living, independence and security; productive and valued activities; the capability to enjoy individual, family and social life; having a voice and influence; the capability of being and expressing yourself, and having self-respect; and knowing you will be protected and treated fairly by the law (2011, pp.116-119), Nussbaum's headings of 'play' and 'other species' were removed through the process. Burchardt and Vizard noted that mental health status was suggested as a possible additional characteristic by their consultees (2011, p.99), suggesting that the social justice of people with mental distress is an issue of 'live' concern to groups experiencing social injustice.

In Wolff and deShalit's exercise they first asked open questions to a sample of welfare service users and providers about what they considered 'basic categories for essential functionings' (2007, p.188) and then posed Nussbaum's list of

central human capabilities on a showcard (2007, p.190). Their findings revealed particular insights from talking to disadvantaged people using the domains framework, for example finding that stigmatisation and loss of social solidarity affected people with cancer, that being completely dependent on others was felt as a great disadvantage, and critique from a disabled person of bodily health and bodily integrity (2007, pp.52-61). Their analysis also demonstrated the feasibility of using this approach to draw out theoretical implications (summarised at 2007, p.181), whilst they also noted the methodological problem of people not speaking about domains that are taken for granted (2007, p.49), dealt with in this study in Section 8.9.6, notably in terms of the value of laughter.

Wolff and deShalit found differences in salience between domains (e.g. affiliation being 'hugely important' (2007, p.54)), a position matched by Nussbaum (2011, p.39). They elicited the most salient domains for the flourishing of their participants using a narrowing prioritisation process (2007, p.106), these being Life; Bodily health; Bodily integrity; Affiliation; Control over one's environment; and Sense, imagination and thought: 'preconditions for the achievement of the other functionings' (2007, pp.106-107) that also enable identification of the 'clustering of disadvantage' (2007, p.107) and therefore of salient risks to social justice. They noted that different 'high-weight' functionings may emerge from other studies.

This study develops Burchardt and Vizard (2011) and Wolff and deShalit's (2007) method of combining of inductive and deductive methods by first interviewing a sample of people with mental distress in an 'open' manner' about their social justice experiences and then using a 'showcard' method to explore how the domains approach illuminates these data. This approach also provides comment on the domains approach itself, a contribution to capabilities knowledge.

Exploring aspects of Burchardt and Vizard's consulted list with a sample of people with mental distress may, first, suggest ways in which their list may be sufficient or insufficient for evaluating the social justice outcomes of people with mental distress. Second, it may identify distinctive weightings and salient domains arising for this social group. Third, a weakness of Burchardt and Vizard was that their classification of participants' responses into domains and sub-

domains did not achieve respondent validation. Their interpretations can appear *prima facie* inaccurate, for example ‘being yourself in public spaces’ (2011, p.106) becomes the sub-domain ‘access and use public spaces freely’ (2011, p.119), each conceptually very different. ‘Being yourself’ in public space in particular may have specific interest to people with mental distress (e.g. Burns et al, 2013), and this study offers an opportunity to probe this capability with a salient group.

Whilst Burchardt and Vizard did not convey any difficulties in either their participants interpreting the domains, or in their interpreting participants’ responses, Wolff and deShalit described receiving ‘a great deal of commentary on the categories’ (2007, p.51), ambiguity in whether functionings were important in themselves or as a means to other functionings (2007, p.50), and idiosyncratic responses reflecting personal experience (2007, p.50). They note the difficulty of conveying domains in an interview setting (2007, p.57), suggesting a challenge in using the domains framework as a qualitative research method. However, there is also an unfortunate terminological ambiguity between ‘domains’ and ‘functionings’ throughout Wolff and deShalit (2007), which creates a conceptual problem as each domain is made up of several functionings, and therefore the two are not the same. These constraints suggest the need for a transparent and vigilant approach to eliciting, presenting and interpreting data gained through the domains approach.

Wolff and deShalit’s data also revealed that within domain headings people could achieve some of Nussbaum’s descriptors but not others, and would not perceive themselves as disadvantaged in this partial achievement. This reinforces a subjectivity/objectivity tension in measuring the achievement of thresholds noted by other authors (e.g. Riddell and Watson (2011, pp.198-199) and Walby and Armstrong (2011, pp.211-212)), not yet explored for people with mental distress.

Further, Wolff and deShalit’s account of their method and transparency of interpretation left a number of ambiguities. The number of professionals interviewed in their study was higher than service users, but the proportions are not clear; they do not describe the process of selection of data; and it is often not clear if a point was made by a service user or by a service provider (2007,

pp.51-61). Their exposition of participants' data on each domain is very uneven: sometimes they provide a short overview of responses (e.g. emotions, 2007, p.53); other domains (e.g. affiliation 2007, pp.54-56) are given lengthy interpretation. They very actively interpret responses at times, whilst at others leave respondents' views to speak for themselves (2007, p.52), each without justification, so overlooking their power as researchers in the interviews and in the selection and interpretation of results. Wolff and deShalit further contended that their method 'overcomes ... biases in the selection of functionings ... [B]ecause it is based on a plurality of sources' (2007, p.61). In addition to the problem of their plurality not being transparent, pluralities are infinite, and this claim is therefore not credible; for example there is no evidence that people with mental distress participated, an archetypal disadvantaged group.

These types of problem result from the philosophical bases of their argument. Ontologically, their interpretation of the world is that service professionals and service users are one category. Epistemologically this leads them to eradicate differences in perspective between the two, as if their interests are identical; in the context of mental distress, the evidence of differences in power between professionals and 'service users' is long-established (Rogers and Pilgrim, 2010, pp.139-147). Ethically this leads them to the position in which the knowledge produced eliminates any conflict between the two social groups involved and so lacks dimensions that are, for example, critical of professional power. In contrast, the present study follows a methodological tradition well established in the sociology of mental distress based on conflict theory, and draws solely on perspectives of people with mental distress.

This section has shown that the capabilities approach can be qualitatively explored both inductively and deductively. The approaches taken by Burchardt and Vizard and Wolff and deShalit suggest that in-depth qualitative exploration of subjective experiences can be combined with a domains-based approach, so holding on to a degree of objectivity in understanding social justice outcomes missing from the U.S based qualitative studies, and exploring social justice beyond service usage. In all this literature however, the operationalisation of capabilities as opposed to functionings, a 'running sore' in capabilities research, is not resolved, and a critical realist epistemology is absent, leading to a rather

reductionist capabilities epistemology by which to understand the lived experience of mental distress.

## **4.6 Fieldwork and analytical choices**

### **4.6.1 Research design**

The purpose of the study was to understand the social justice of people who have had recent experience of voluntary or compulsory admission to a psychiatric ward, in terms of what participants were able to be and do, for the purpose of normative and theoretical insight. In this regard the research design was strongly influenced by Barham and Hayward (1991).

This was designed as a two-stage fieldwork study, informed by literature, using semi-structured in-depth individual interviews, stage one being more inductive, stage two more deductive using the domains concept. This approach follows Alkire's (2007, p.13) methodological note on capabilities inquiry, that 'researchers will generally use two or three methods in an iterative approach'. One-to-one interview techniques were employed, rather than group-based methods for three reasons. First, to create data of singular experiences, maximising clear personal narratives. Second, as the interaction of capabilities with lived experience was quite unexplored, the study would benefit from maximising the diversity of lived experiences, unmediated by group norms. Third, as the data may include personal experiences of a sensitive nature this approach would maximise confidentiality (Hennink et al, 2011, ch.6).

An interview focus on functionings and capabilities in the context of mental distress can draw out empirical data, revealing that which is closed to macro-level analysis. This 'survivor knowledge' (Beresford, 2005) has its own significance in a field 'dominated by medicalised frameworks for analysis and 'treatment'' (Beresford, 2005, p.40). However it still holds limitations, notably including evidence that although 'depression' is socially constructed (Pilgrim and Bentall, 2003) those with current experience of depressive feelings may be less likely to feel wellbeing (Scottish Government, 2009, p.5) and may have negative recall (Bentall, 2003, pp. 247-250). Although contradicted by Wallcraft (2011, p.271), this may impact on subjective understanding of functionings and

expectation of capabilities (Gandjour, 2008), suggesting that care in interpretation is required. Alongside cross-case comparison, intensive analysis conveying the richness of the data, and transparency about the limitations of the sample achieved, this shall boost the achievement of quality indicators for qualitative studies (Spencer, 2003).

Interviews were all conducted face-to-face in order to maximise rapport with participants; to allow any emotional issues raised during the interview to be managed in a safe environment; to enable body language to additionally inform the researcher's interpretation; and to allow the researcher to write more complete reflexive notes on the interview environment.

At stage one twenty-two individual semi-structured face-to-face interviews about the kinds of things that participants had done and been, and felt were possible to do and be, in life were conducted, lasting on average one hour. The interview guide (Appendix five) was informed by the research questions for the study and the literature reviews of capabilities and mental distress, whilst allowing respondents space to prioritise topics that mattered to them. Approximately six months after their first interview, sixteen consenting stage one participants took part in a second stage semi-structured individual interview exploring themes emerging from stage one, including application of an adapted version of Nussbaum's (2006) and Burchardt and Vizard's (2011) domains frameworks.

#### **4.6.2 Sampling strategy**

The purpose of the analysis was to gain theoretical insights, so making a contribution to contemporary conceptual, methodological and theoretical arguments in relation to both capabilities and social perspectives on mental distress. Therefore the sample of participants did not seek 'representativeness' of people with mental distress; it was a purposive sample, with generalisation to comparable populations or geographical areas being made only tentatively.

In Baker and Edwards (2012), Becker (2012) argues that whilst a very small number of interviews can demonstrate that a phenomenon is more complex or varied than previously thought, the researcher should be minded of how many



interviews would be needed to convince a sceptic; Jensen emphasises quality over quantity in terms of the dignity, care and time taken over the analysis of interviews; Adler and Adler suggest that thirty interviews is the mean for qualitative studies, whilst noting that for deviant or elite groups six to twelve may be adequate. Taking account of these arguments, the study aimed to recruit up to thirty people living in Glasgow about their experiences of life after psychiatric hospital since the implementation of the Mental Health (Care and Treatment) (Scotland) Act 2003 in January 2006. This also limited temporal criteria to those that had been recently hospitalised, and under a common legal framework, seeking to reduce 'retrospective bias' (Hopper 2009, p.6, n.13).

The criteria of psychiatric hospital admission since the implementation of the MHA 2003 was the sought common experience within the sample, from which attendant impacts of diagnoses, treatment, and post-hospitalisation could be explored. Hospitalisation would be a cipher for a certain significance of subjective mental distress experience, so avoiding critiques of the analysis being of those with 'minor' or 'trivial' distress experiences (unless hospitalisation was unjust, which may have emerged) whilst not following the epistemological 'trap' of the label or diagnosis being a cipher for severity of distress experience, risked by Barham and Hayward (1991).

These inclusion criteria embraced people that had experienced multiple hospitalisations including before 2006, or a single admission since then, and those who had voluntary or compulsory admissions, and both. Recruitment was of people not currently in psychiatric hospital or subject to a CTO in order to positively recruit people that were currently 'free' of the mental health system. This avoided the need for the NHS or psychiatric services to be 'gatekeepers' and their consenting to the study becoming an ethical requirement. The sampling strategy therefore followed Estroff (1981, pp.215-216):

The clients in my project had already experienced primary symptoms, and had been diagnosed, labeled, recognized, and treated before my contact with them began. Therefore, my focus was on their reactions, adjustments, rejections, and acceptances of their labels and/or illnesses.

Whilst Estroff's working assumptions were that the individual's 'perceptions, beliefs, feelings, experience, and behaviours constitute the most important unit of analysis and understanding' (1981, p.37), her data was not treated uncritically but analysed using symbolic interactionist, labelling theory and deviancy viewpoints (1981, p.40), as Barham and Hayward analysed their subjective data using Taylor's quality of life model alongside Dahrendorf's conflict theory (1991, ch.7). This study builds on these methodological approaches, taking a different turn from Estroff in using interviews rather than ethnography as the primary data source, but following her in taking a weak constructivist approach to the data, in contrast to Barham and Hayward who allowed their data to sit rather uncritically alongside the analysis.

Geographically the sample was sought within Scotland as mental health policy is devolved within the UK, with distinctive legislation (e.g. MHA 2003), policy frameworks (e.g. The National Programme for Improving Mental Health and Well-Being in Scotland), anti-stigma campaigns (e.g. See Me), sources of support (e.g. Breathing Space, Choose Life, Action on Depression), and professional-public networks (e.g. Scottish Recovery Network). To narrow this further, the study recruited people resident in Greater Glasgow. This would allow a focus on social justice variability within a single Health Board area (Greater Glasgow and Clyde) and mainly within one local authority funding and policy regime, with a common infrastructure of local social care and voluntary organisations. To explore within one national legislative and local policy boundary implied that in the analysis of the social Conversion Factors, some variables may remain constant, their subjective implementation and impact becoming of interest to the analysis.

In Barham and Hayward's (1991) study, their sample was insecurely employed or living on social security, leaving them in a 'predicament'. What they achieve is a focus on a group of people with mental distress that lack economic and cultural resources to change their situation. This enables a sociological focus on the forces that leave them excluded. What Barham and Hayward miss are examples of people that have mental distress and experience social justice, risking their reinforcing a 'tragedy' narrative. A broader approach to recruitment was therefore required both to seek a range of experiences as well as for practical reasons of achieving sample size, given the time constraints of the study. It was

emphasised to gatekeepers that I was seeking to include people experiencing different types of social justice.

Barham and Hayward (1991) recruited mainly men due to their sampling constraint of focusing on people with diagnoses of schizophrenia. Reflecting the national picture, Shipton and Whyte (2011) report that males in Greater Glasgow and Clyde Health Board area were almost twice as likely as females to be discharged from a psychiatric ward with a diagnosis of schizophrenia; women were 50% as likely as men to have a mood-related psychiatric discharge. Therefore recruiting participants with varying experiences of diagnosis was felt more likely to elicit a sample equally weighted by gender, allowing the analysis to indicate any gendered differentials in social justice experiences.

In terms of age, Barham and Hayward's (1991) sample were mainly twenty-five to forty-five, which enabled their participants to explore having an adult past with mental distress, but also an adult future to be contemplated. This study instead sought adults aged 18 to 65, again for methods of practicality of seeking sufficient sampling size.

Previous qualitative studies had neglected ethnicity. In the Glasgow context, asylum seekers and refugees form part of the community and people from a Scottish Pakistani background form the largest ethnic sub-group of the general population. These groups may have distinctive constraints on what they are able to do and be, for example asylum seekers are not able to work, and may use distinctive support networks. Although ethnic minority participants were sought, including through specialist voluntary sector organisations, no participants explicitly identifying as ethnic minorities were interviewed. Therefore this remains a gap for future research.

There were resource and practical implications in making sampling choices: face-to-face fieldwork needed to be managed within a budget; visits to recruit gatekeepers, recruit participants, and then to research participants' experiences over two interviews, required funding. Rural interviews would be problematic due to my need to use public transport. Recruiting within Glasgow was pragmatic for these reasons too.

So the answers to the research questions were to be sought through a theoretically purposive and pragmatic sample of people with recent experience of psychiatric hospital, including voluntary admissions. Participants would therefore have a wide range of admission experiences, from a single admission (indeed for one instructive participant, no admission) to multiple, would live in Glasgow and would be anticipated to have a range of social justice experiences.

### **4.6.3 The recruitment process**

Voluntary sector organisations perform a specifically important role in the lives of people with mental distress, providing advocacy and practical support, and mental health voluntary organisations had been used to successfully recruit for a previous study (Stalker et al, 2011). Participants were therefore initially recruited through mental health groups in Greater Glasgow and Scottish mental health networks. The purpose and ethics of the study and the recruitment criteria were explained to gatekeepers at these groups and, if they consented, their organisations electronically or otherwise sent the recruitment advert (Appendix one) to their members. With two organisations, a theatre group and music group, I attended a members' meeting to recruit. I then recruited through posters on the University of Glasgow campus, including in student Disability Services, and recruited one interviewee through a personal contact. Successful recruiting organisations were as in Table 1:

Organisation	Number of round one participants recruited
Local mental health user network	7
University poster	4
Scotland wide mental health e-newsletter	3
Mental health theatre group	2
Mental health music group	2
Personal contact	1
Advocacy group	1
Saw poster in local British Legion club	1
Saw poster in Clubhouse	1

Table 1: recruitment sources

By using several types of network for recruitment, I sought to offset dependence on one gatekeeper to recruit, and to recruit some participants not using voluntary organisations.

Recruiting through organisations risks the gatekeepers recruiting those who they see as most ‘likely’ to participate or having a particular interest in the study, meaning that recruits may have been of a particular type of ‘active’ mental health service user. This was addressed by being clear that I was seeking a wide range of people, not necessarily ‘activists’ and that I was seeking people in particular that may be less active users of the group. Second, gatekeepers may encourage participation by service users viewed as sympathetic to their organisation, leading to data being skewed by participants uncritical of their supporting organisations (Emmel and Hughes, 2009, p.328). This was addressed through clarifying the non-evaluative role of the study with gatekeepers and

with prospective participants, alongside commitments to confidentiality and anonymity of organisations and individuals in the write-up. Participants were also asked to contact the researcher directly rather than going through the gatekeeper, providing more researcher control and respondent autonomy. Recruiting through voluntary organisations also meant that participants were involved with a support network, rather than living a more 'disconnected' or independent life, and recruiting through the University led to a potentially different skew. This required reflexivity in the analysis.

The recruitment advert asked prospective participants to contact me directly by letter, email, or via a mobile phone bought specifically for the purposes of the project. It specified the recruitment criteria, namely to have been a voluntary or compulsory patient on a psychiatric ward for any period of time since January 2006, resident in Glasgow, aged 18 to 65, and not currently on a Compulsory Treatment Order. It added that they may still use psychiatric services, or may see themselves as 'recovered', included to convey a message that the study was not seeking a particular 'type' of experience. The advert was framed to avoid medicalised terminology and specifying that this was a social science study, so by implication not a medical or psychological study. The advert also made it clear that I was a former mental health advocate, in order to inform prospective participants that I had experience of being on the side of mental health service users, again suggestive that I was not approaching the study from a medical perspective.

Twenty-six people made contact, four of whom did not reach the criteria, two due to lack of in-patient experience and one living outside Greater Glasgow. Barham and Hayward (1991), monitored several characteristics of their sample, aiding the reader in interpreting, and adding transparency. The reader can see that their sample is heavily skewed towards men, not in work, almost all on psychotropic medication, living in council accommodation or hostels, having a mean duration of mental distress of sixteen years, with six hospitalisations each and first hospitalised on average at age twenty-three. These characteristics are reflected through their analysis where tensions around finding work, forging identity, developing social and intimate relationships, gaining secure and suitable housing and extricating themselves from poverty dominate the findings: all key issues related to social justice. The present study initially aimed to

collate demographic data systematically (see Interview one guide, Appendix five), with the purpose of providing a similarly full picture of participants. However, the diversity of the sample, less formal recruitment processes, and more relational and critical understanding of categorisation in the present study made these data more fluid.

Data on participants is in Table 2, below. The table includes a number of clauses: ‘approx’ meaning that the person could not confidently recall. d/k means that either the person did not know, or the question was not asked. n/a means ‘not applicable’. The medication and diagnostic data use participants’ lay descriptions. As each interview was individual, not all categories in the table were covered for all participants. All data in the table relied on accuracy of recall, cognition and explanation. The problems of recall matched with the time limits and breadth of interviews, suggest that the table will tend to underestimate rather than overestimate historical data such as medications, diagnoses and numbers of hospitalisations; indeed some participants were explicit about this (e.g. Caroline: ‘I’ve just had one extended period in hospital’, discounting possible shorted stays).

Four of the twenty-two successful recruits did not transpire to have clearly had in-patient experience since January 2006, or were uncertain due to problems of accurate recall. Only one participant was accepted with no experience of being an in-patient, Becky, as she had argued very strongly to avoid becoming an in-patient as her father had a grim experience of being an in-patient. This suggested that she did not necessarily have ‘milder’ experience of mental distress than any other participant, but a distinct social context. I felt that her experience might shed light on the majority experience. The criteria of ‘since January 2006’ helped to elicit participants with recent experience of hospitalisation, even if not strictly within that time period. In the interviews very few participants referred to the MHA 2003, reinforcing evidence of its minor impact on mental health service users (Griesbach and Gordon, 2013).

Pseudo-nym	Partici-pant in interview 2	Age at interview 1	Age when first hospitalised (approx)	Number of hospitalisations (approx)	When last in psych hospital (approx)	Psychiatric diagnoses: subjective recall	Prescribed psychiatric medication(s): subjective recall	Talked about suicidal feelings or self-harm	Housing type and living status at interview 1	Current income and employment status
Lawrence	Y	31	24	3	Dec-08	schizo-affective disorder, bipolar disorder	Lithium	N	Private rent with partner	F-T employment
Fiona	Y	58	46	3	Sep-11	manic depression	Lithium, ECT	N	Public rented flat on own	3 hours/week work (cleaning) + benefits
Jack	N	40	22	4	Late 05	Personality disorder, drug-induced psychosis, polysubstance dependent	d/k	Y	Private rented flat on own	Benefits (volunteer at MH organisation)
Arthur	Y	48	24	3	Six or ten years ago'	Depression, manic depression, schizophrenia	Depot injection plus tablet (unspecified)	Y	Public rented flat with partner	Benefits
Harry	Y	56	51	1	Oct-07	Depressive and anxiety disorder; depression	Citalopram. Occasionally also Diazepam	Y	Rented flat with partner	Benefits
Robert	Y	56	39	3	2007	Depression and anxiety	Amitryptilene	Y	Supported housing	Benefits
Becky	Y	25	n/a	0	None	Hypomania, depression	Antidepressants; valium	Y	Room in flat owned by friend	Student (UG)
Barbara	N	56	29	2	1993	Manic depression	Trasadol	Y	Public rented flat on own	Benefits
Martin	Y	51	31	2	2007	paranoid schizophrenia,nervous breakdown	Depot	N	Public rented flat on own	Benefits
Monica	Y	50	30	Many (3 sections)	2013	Bipolar, personality disorder, depression and psychosis	Past - chlorpromazine . Now: Aripiprazole (atypical antipsychotic) and an antidepressant.	Y	Housing Association flat, on own	Benefits
Francine	Y	31	29	2	2010	Depression	fluoxetine, Venlathaxine, Lithium	Y	Mortgage, on own	Student (UG)
Kirsty	Y	26	15	3	2006	Depression	Prozac, Seroxat, tricyclic antidepressants, Sertraline	Y	In boyfriend's mortgaged flat	Student (PG)
Gary	N	45	42	1	2009	Depression, bipolar, hypomania	Amitryptelene, Depakote, Quetiapine, Quetiapine XL	Y	Public rented with wife and 2 youngest children	Benefits
Ivy	N	56	30	2 (min).	d/k	Schizophrenia	Clozapine and others (unspecified)	N	Public rented, on own	Benefits
Tim	N	37	32	1	2008	Personality disorder, psychosis, bipolar, depression	At interview 1: Sertraline (depression), diazepam (anxiety) and triazepam (sleeping)	Y	Housing Association flat on own, with child at weekends	Benefits
Sophie	N	25	23	3	2010	Depression, prodromal psychosis, schizophrenia	At interview 1: Quitiapine (antipsychotic), Lamotrigine (mood stabiliser), Sertraline ('for anxiety'). Past: Olanzapine [antipsychotic], Amisulpiride [antipsychotic].	N	Private rented flat with partner	Student (UG)
Lara	Y	24	16	5	2013	Depression, post traumatic stress, bipolar, emotionally unstable personality disorder	At interview 1: Quetiapine. Past: antidepressants	Y	Housing Association flat, on own	Benefits (volunteer at Clubhouse)
Jon	Y	35	21	2	2007	Anxiety/depression, nervous breakdown, bipolar disorder	Lithium, Citalopram, beta blockers	N	Private rented flat, with mother	Benefits
Bridget	Y	43	16	multiple, I couldnae count'	2010	Personality Disorder, paranoid schizophrenia, bipolar and schizophrenia, schizo-affective disorder, postnatal psychosis	Clozapine, Lithium, ECT maintenance dose	Y	Public rented house, on own	Benefits
Jim	Y	64	d/k	4 in last 2 years	d/k	Well they say I'm bipolar which means I'm manic depressive and hypomanic'	Lithium, sometimes Chlorpromazine	Y	Private rented flat, on own	Benefits/pension
Caroline	Y	24	d/k	one extended period ... just under four months'	d/k	Depression, PTSD, Bipolar	At interview 1: a mood stabiliser, anti-depressant and anti-psychotic and a prn sleeping tablet	Y	Room in flat owned by friend	Benefits
Steve	Y	50	43	1	2006	Depression	At interview 1: Antidepressant	Y	Mortgage, with partner and son	F-T employment

Table 2: research participants



In sum, the sample was eleven men and eleven women at interview one, and eight of each at interview two. At interview one the age range was from 24 to 58 with age of first psychiatric hospitalisation ranging from 15 to 51. Almost all participants lived within the city of Glasgow. Eleven participants lived alone. Twelve lived in public rented housing, seven in privately rented, three in mortgaged accommodation. Sixteen participants were on benefits, several of these also with small jobs or volunteering; four were students; two were in full-time work. Seventeen participants had definitely been on a psychiatric ward since January 2006. Collectively, participants recalled 49 periods in psychiatric hospital in their lives, although this was much higher as several had multiple admissions, some limited their definition of this to recent times or longer stays only, and the interviews were not focused on exhaustive specification. Only four participants definitely had only a single admission; 11 had experienced three or more. Specification of prescribed psychiatric medications and diagnoses was similarly broad due to subjective definitions, problems of recall and lack of exhaustiveness. However, only five participants recalled receiving a single diagnosis; seventeen had received more than one. Sixteen participants described self-harm or suicide attempts.

#### **4.6.4 Ethical procedures**

The University of Glasgow College of Social Sciences Ethics Form was completed with reference to the Statement of Ethical Practice for the British Sociological Association (March 2002) and Social Research Association Ethical Guidelines (December 2003). The application was reviewed and approved by the College Research Ethics Committee on 6 November 2012, Ethics Reference No. CSS20120222.

Following College of Social Sciences Ethics Guidance, a Plain Language Sheet (PLS) (Appendix two) was produced. Once prospective participants had made initial contact, this was emailed or posted to them prior to meeting for interview, and their comprehension of it discussed prior to completing the consent form (Appendix three) before the interview itself, not assuming literacy, and seeking to maximise understanding. The PLS clarified the inclusion criteria, the confidentiality and anonymity terms of the interview, and the funders.

Interviews were audiorecorded with consent, with clarity provided over anonymity, confidentiality and destruction of the data. As this was an ESRC-funded study, the ethical application proposed that if the data from the study could be anonymised in an efficient amount of time whilst retaining its integrity, it would be electronically transferred to ESRC Economic and Social Data Service (ESDS) for the purposes of archiving within three months of completion of the study. This was explained to prospective recruits, and was included on the consent form for the study, their inclusion in the study not being contingent on their consenting to this. At interview two, participants were reminded of the terms of their consent at interview one in order to allow them to change the terms of their consent if desired.

Signed consent forms and the data audiorecorder were stored in a locked filing cabinet at the University of Glasgow. Transcripts were identified only by participant initials, gender, age and interview location. All electronic data was stored in password protected folders at the University of Glasgow. The ethical application proposed that all paper data was to be shredded and electronic data deleted once all publications arising from the study had been written.

No financial incentives were provided to participants. Travel expenses were paid and refreshments provided.

#### **4.6.5 The interview process**

First interviews were conducted between December 2012 and March 2013; second interviews between July and October 2013. The interviews offered participants an opportunity to talk about their life as a whole, rather than focusing on service provision, as much research with this population does (Rogers and Pilgrim, 2010, pp.242-251). Potential participant benefits included involvement in a study aiming to gain a normative understanding of social justice for people with mental distress, with outputs including a plain English summary of findings for participants and recruiting organisations, aiming to enhance their understanding, so enabling some direct impact from the Ph.D.

Interview locations were negotiated with each participant. I arranged interview space at the Universities of Glasgow and Strathclyde, and some of the voluntary

organisations provided a confidential space for interview at their offices. Some interviews took place in participants' homes, one at a workplace. Craig, Corden and Thornton (2000) have noted that precautions used by social researchers should be reasonable, with safety considered from the perspectives of both the researched and researcher. There was therefore a balance to be achieved between confidentiality and safety. My previous experience (chapter one) enabled me to safely negotiate interview locations with participants.

As part of the recruitment process I spoke to or emailed prospective participants prior to meeting them in order to develop initial rapport to continue through the research arc. This would have allowed me not to select people if, in the course of this relationship-building I had concerns about their informed consent to the research process or any other factors which may affect data reliability or participant or researcher health and safety.

Lee (2004 cited in Bryman, 2008) has distinguished between ambient and situational risks in fieldwork. The evidence for people with mental distress living in the community being more dangerous to other people than any other citizen is weak (ODPM, 2004, p.25) and remains a problem of public perception (ODPM, 2004, p.26). Therefore, precautions for risk in terms of location for interviews were required to be taken from the general location of participants, or ambient risk, more than from the participants themselves. When interviewing in participants' homes this was done within public rooms with my first supervisor being informed of where, when and who each interview was with, and informing them by telephone on completion of each interview.

My previous experience had provided me with the skills of conducting ethical and safe interviews with people in varying states of mental distress, including appropriate seating arrangements, creating rapport, speaking clearly and framing questions straightforwardly, listening attentively and with care, leaving silences, fitting the communication preference style of the interviewee, techniques of asking difficult questions and negotiating withdrawal from interview. Using these skills, I established the appropriate social distance throughout the recruitment process and in interviews (Craig, Corden and Thornton, 2000). The study purpose was verbally explained at the start of both interviews to support the Plain Language Sheet and to maximise understanding

of the focus of the research. Each interview ended non-abruptly, with space for interviewees to ask questions about the research, and to reflect on what they have talked about. This aimed to minimise the possibility of interviewees withholding concerns that they wished to express.

At interview two, recruitment was by phone call, letter or email from me, dependent on contact previously established, including information that the second interview would follow up one or two points from the first interview, and would include 'questions about a framework that attempts to understand the things that help people to thrive in life, to see what you think about it' (see sample email Appendix four). It reiterated that the interview would again be solo, audiorecorded with consent, and confidentiality and anonymity were clarified. At stage two, one person was in psychiatric hospital and did not wish to participate for that reason. Several did not respond to my contact, and a couple of participants were non-contactable, having ceased contact with the voluntary organisation or changed telephone number, reducing the number of participants from twenty-two to sixteen.

As with any study, these preparations did not discount the possibility of participants becoming stressed in the course of the interview due to mental distress or any other factor. The fieldwork was organised to maximise the possibility of this being revealed in advance of any interview, indicated through atypical communication to that generally established, through the process of emails and calls to make arrangements for the interview. I was always clear with participants that they could postpone or cancel our meeting for any reason, including in relation to their own mental health or a wish to reconsider or withdraw from the project as a whole. Several stage one interviews were postponed by participants and two second interviews were cancelled by participants after arranging dates, the reason not being clear.

From the perspective of the researched, the possibility of sensitive issues being raised in interview which may risk harm was minimised by providing respondents with advance information on the themes proposed for discussion. A commitment was made on the ethics application to provide participants in crisis or who became emotionally affected by the interview with information on places to obtain support. No issues of this type arose.

### 4.6.6 Data collection strategy

As little was known about how the capabilities approach related to people with mental distress, stage one interview questions were framed with implicit regard to capabilities concepts to enable social justice issues to be induced from the interviews and then be re-interpreted using capabilities concepts.

#### 4.6.6.1 Interview one

This interview (see interview guide Appendix five) was about the flow of the person's life including how what they had been able to do and be may have been influenced by their mental distress and experience of the psychiatric system. The interview aimed to get within the grain of activities and relationships in the person's life - doings and beings - and was thus framed with regard to capabilities concepts and the literature on the social justice of people with mental distress. To be sufficient, the narrative arc for the interview needed to cover the period from when participants were hospitalised since 2006. However, for some the story necessarily incorporated hospitalisations going back much further.

The interviews were conversational and discursive, Interview One always starting with *'Can you tell me a bit about who you are, where you live, and what you generally do with your day?'* in order to avoid focusing on mental distress from the outset, and enabling participants to talk about their current functionings unbounded by this specific feature.

Every participant then provided in-depth, complex descriptions of their subjective experience of mental distress and their interactions with the mental health system in response to question two *'Can you tell me a bit about your history in terms of mental health?'* Whilst the sociology of mental health can be ambivalent in relation to whether analysis of subjectively experienced mental distress matters, Tew et al (2006, pp.19-22) convincingly argue that this position is in conflict with taking user accounts seriously. I took care to allow participants to select the terminology in which to frame their experiences, to avoid presumption that participants' understandings would be either medically or socially framed, or experienced as positive or negative. The wide range of

descriptions given demonstrated both that subjective understanding need not be dominated by medical hegemony, and that sociologically-framed questions need not tautologically elicit social responses.

Discussions then became more fluid. Question 3 focused on what people currently did, their functionings, and their subjective view of these, aiming to identify examples that got to an understanding beyond utilitarian measures. Question 4 focused on capabilities, the capability set and capability deprivation. Question 5 aimed to develop an understanding of subjective experience of social justice both within psychiatric system experiences and in wider social life using the concept of fairness. Question 6 pushed at the capabilities notions of freedom, diversity, agency and adaptive preferences, alongside the more sociological notions of stigma and harassment to understand participants' experience of domain thresholds in relation to safety being upheld, and to explore whether there was a relationship between their mental distress experiences and these capabilities notions.

Asking whether people were able to 'be themselves' with mental distress or whether people needed to adapt their behaviour in order to gain social acceptance sought to draw out experiences of adaptive preferences in response to dominant social norms. This question proved hard to frame and tended to be understood by participants in a way that engendered the observation that their personal behaviour was adapted in many contexts. However, adaptive behaviours were sometimes revealed earlier in the interview, with several participants talking of hiding the expression of their mental distress from family, in public or at work.

#### **4.6.6.2 Interview two**

Adapting Wolff and deShalit's 'showcard' method (2007), two Capabilities Domains Diagrams entitled 'Ingredients for a thriving life that a person values and would choose' were devised, one being 'easy read' (Appendix eight), and piloted with peers. This was used as a tool to facilitate the second interview discussion on the domains approach (Interview two schedule - Appendix six). After piloting, 'thriving' was used in the title, in contrast to 'flourishing' as used

by Burchardt and Vizard (2011), as it captured a similar quality in language that was felt more likely to achieve lay understanding.

The diagram was based on the ten domains resulting from Burchardt and Vizard's (2011) consultative exercise. However, as Alkire (2007, p.12) has suggested, domains that are not directly related to poverty reduction, which might be viewed as frivolous or marginal to explanation of social injustice, can become central. The first round interviews suggested that wider domains may indeed be of salience to the sample. Thus, two of Nussbaum's (2006) domains, removed from Burchardt and Vizard's consultative list, were added to the Capabilities Domains Diagrams ('Play' and 'Other species'). An 'Anything else' domain was also added to the diagram to facilitate free response, mirroring Wolff and deShalit's approach (2007, pp.60-61). The in-depth, semi-structured approach of the interview two schedule aimed to encourage discursive responses, so allowing 'expanded capabilities' to emerge (Alkire, 2008) - dimensions of quality of life that were specifically important to the lived experience of people with mental distress.

In their paper (2011, pp.116-119), Burchardt and Vizard listed sub-domains in order to exemplify or specify the intended content of the domain heading drawn from their study, as Nussbaum provided short descriptions under each domain heading (e.g. 2006, pp.76-78). Whilst Wolff and deShalit included Nussbaum's descriptors on their 'showcard' (2007, pp.51-57), descriptions were not shown in my diagrams, only domain headings. Any requested clarifications (very few) were provided verbally by my summarising Burchardt and Vizard's examples or Nussbaum's description accordingly.

The stage two interview process was as follows (Interview Schedule, Appendix six). After an 'update' conversation about what people had been doing in the six or so months following the first interview, participants were asked their subjective view of whether they were currently 'thriving' or 'getting by'. The diagram was then shown and verbally described as being a discussion tool based on the work of Burchardt and Vizard and Nussbaum. A verbal description of the normative intent of the domains - that all were required to have a thriving life - was given (following Wolff and deShalit, 2007, p.40), and each of the twelve domains read out, pointing to them on the diagram. It was emphasised that

there were no right or wrong answers, and that I just wanted to know what the interviewee thought. Two negative comments were received on the 'thriving person' pictured at the centre of the diagram (Appendix eight) - one that it looked like a person using a phone box, and one that it looked like a 'desperate person' rather than a thriving person.

The discussion generally continued by my checking that the respondent had understood the domains, followed by asking '*what do you think?*' Participants would commonly start by talking about particular domains and the discussion would flow with a mixture of silences, open questions, '*any others?*', and sometimes detailed conversation, notably when participants queried the apparently simplicity of the model, bringing in complexity. There was no aim that participants should comment on all domains, so participants led those that were most salient. Question four pushed at whether functionings or capabilities were important to people, pressed the issue of threshold breaches and security of domains and responsibility for achieving these, and asked about the 'being healthy' domain, informed by the mental distress literature. Question five asked people if they could identify the least important domains to their thriving. The 'anything else' box was then introduced. Question eight ('*How would you now say you have you been doing...?*') was asked only if this would add something not already gained (rarely), and question nine ('*How was that experience for you?*') asked almost every time in order to provide reflexive data for capabilities scholars on the use of the diagram as a research method.

So stage one sought a 'bottom up', inductive view of social justice. Stage two explored whether capabilities domains evaluating social justice emerging from consultation with other excluded groups 'spoke' to people with mental distress, deducing data, and offered them a means to amend or expand these. In Stage one, capabilities was used in a loose sense to structure the interviews, in Stage two it was used in a strong sense.

As an example of the benefits of this approach, the data on the deprivations of the capability to have children only emerged in response to the diagram, stemming from the domain 'enjoying individual, family and social life' (section 8.9.9). This demonstrates a benefit of using a more structured and objective



approach to questioning, in contrast to a more open-ended, subjective approach.

#### **4.6.7 The interpretation of interview data**

The data analysis process was influenced by Spencer, Ritchie and O'Connor (2003) and Ritchie, Spencer and O'Connor (2003). All participants at stage one interview gave consent for interviews to be audiorecorded, except one for whom notes were taken, as did all participants at stage two. Several interviewees had strong accents and/or possible oral iatrogenic effects, so recording the interviews helped accurate interpretation. Following the method of Lofland and Lofland (1995, pp.87-89), at each stage recordings were listened to immediately following the interview, and a thick description of each typed in order to develop a clear immediate narrative and to create 'tentative little pieces of analysis' (1995, p.88) that may become codes or memos. Samples of the thick descriptions were given to supervisors and interpretations discussed. Care was taken to both seek emergent themes and not to close down the analysis too early, using the process to open up ideas that may connect with later interviews.

Each interview was then transcribed verbatim and inputted into Nvivo10. For time efficiency, five stage one interviews and fifteen stage two interviews were transcribed by a professional transcriber used in a previous study (Stalker et al, 2011), all others being transcribed by myself. A confidentiality and data protection agreement was signed by the transcriber (Appendix seven). All professionally produced transcripts were checked on receipt for accuracy by listening back to the recording. A small number of minor changes were made. I therefore listened to each interview once live, a second time immediately afterwards, and a third time whilst transcribing or checking a transcript. Whilst doing this I was able to gain greater understanding of each interview, providing further insight into the initial 'thick description' of each interview.

The theme development process for stage one consisted of both thick descriptions and interview transcripts being imported to Nvivo10. Initial nodes and sub-nodes were created in Nvivo10, starting from an initial set of themes that had become visible from the thick descriptions and transcribing process. The nodes and sub-nodes were thickened, amended, sub-divided, merged or

removed in an iterative process as transcripts were read through within Nvivo10 and sections of text swept into relevant nodes and sub-nodes. Once this process was complete, the data in each individual node or sub-node were read through systematically and interpreted in writing to understand the range of what participants had said in relation to that theme.

Three initial nodes representing the broad, early themes of the stage one interviews were created: subjective experiences of mental distress; meaningful and valued activities; and social relations. As transcripts were read through several sub-nodes developed. For example 'subjective experiences' had: subjective cause of mental distress; subjective description of mental distress; physical health connected to mental health; child and adolescent wards; suicide and self-harm; hospital-related experiences; diagnosis or label experiences; medication experiences; psychological interventions; social interventions; relations with professionals. Each of these then developed one or more sub-nodes, for example, 'hospital-related experiences' had sub-nodes of admission experiences; in-patient experiences, discharge experiences; outpatient experiences; and mental health law. These then developed further sub-nodes, for example 'discharge experiences' had two sub-nodes (good discharge; bad discharge); in-patient experiences had ten sub-nodes, including good care by staff; having life saved; making things worse or not helping; medication issues; bad care by staff. So, through line-by-line systematic analysis of the transcripts, four levels of node were developed, reflecting the density of the data and intensity of analysis.

Prior to the first interviews, given Newton et al's (2000, p.485) finding that people with a 'severe mental illness' were often difficult to interview due to the presence of symptoms and their sometimes withdrawn state, I anticipated that the second interviews would be needed to significantly clarify and extend data from the first interviews. However, challenging Newton et al, the first interviews were so full of relevant data that this revisiting process formed a minor part of the second interview, done in most cases to enable reflection and updating from each participant's perspective and for myself to ask minor clarifying questions. These 'updated' data were added to the stage one nodes and levels of sub-node using the same systematic process, and interpretations revised accordingly, reported in chapters five, six and seven.

This outcome provided an opportunity to use most of interview two to explore an originally adapted version of Nussbaum (2006) and Burchardt and Vizard's (2011) domains framework with participants.

For analysis of stage two domains data, thirteen nodes were created in Nvivo10 in advance, corresponding to the twelve domains in the diagram plus the 'anything else?' option. The sixteen transcripts and sixteen 'thick descriptions' were also imported to Nvivo10. Discussions by each participant on the thirteen nodes were swept into these accordingly, and then the cumulated data in each node read through, as for stage one, to interpret what participants had said. No sub-nodes were created as the data was more structured, and so less complex and wide-ranging, than at stage one. Several additional nodes were created to cover emergent dimensions related to the domains, namely; saliency of domains; whether the participant had always achieved thresholds; comments on the diagram and process; interrelations between the domains; any data on functionings versus capabilities; and whether participants viewed themselves as currently 'thriving' or 'getting by'.

For each stage, nodes and levels of sub-node were prioritised for write-up by making three judgments. First, salience: did many participants have data in the node/sub-node, or did a few participants have a lot of data there? Second, if only few participants or a small amount of data was in a node/sub-node, could this demonstrate in-case or small group significance, something happening to one or a few people indicating a significant exceptional narrative on the research questions (Bryman, 2008, pp.55-56)? Third, how did the node/sub-node in question and the data within the node/sub-node relate to the theoretical and empirical literature in the sociology of mental distress and capabilities? This interpretive process continued until a secure understanding was gained, enabling the account to develop from descriptive to explanatory (Ritchie, Spencer and O'Connor, 2003), with the knowledge that the data are always partial and non-exhaustive, in line with qualitative data analysis, critical realist and capabilities principles. The way in which these interpretive judgments were made is conveyed in the data chapters. A research diary was also kept throughout, recording researcher reflections on patterns and meanings within the data, and theoretical and conceptual ideas including those emerging from conversations

with other PhD researchers, conferences, literature and supervision, adding to this iterative process.

If 'user experiences' were to be respected they must be understood not as mere social constructions or mere 'truths', but analysed critically (Zimmerman, 2006). Participants' explanations were treated as subjective perceptions, illuminating the complexity of social facts and people's ethical assumptions and expectations as expressed in the context of a research interview. The character of the first interview data in particular was complex and contradictory, each 'case' holding distinctive elements, whilst some cross-case comparison emerged. Ambiguity in responses was a reflection of the semi-structured study, in which interpretation of the questions by both interviewer and interviewee was subjective, with agency, especially at stage one, being handed to the interviewee to decide how to focus their answers. This reflects two of the five value based principles for mental health research of Tew et al (2006, p.vi): partnership and recognition of social diversity.

Therefore alertness to participants' descriptions in relation to dominant understandings of mental distress was required, whilst not being overly focused on specific terms used (for example 'illness', 'label' or 'diagnosis'), so producing a weak social constructivist analysis, beyond discourse.

Participants' salience tended to shape the data prioritised for write up at stage one, treated critically and with regard to the literature; a strongly inductive approach. At stage two, as views on the concept and detail of the domains framework were sought, a more deductive approach, this structured the interpretation, which was again treated critically and with regard to the literature.

Although the interview questions and the analysis of the data were framed by concepts developed in the mental distress and capabilities approach literature, analysis also required paying attention to understanding participants' responses beyond the context of capabilities and social perspectives: this is a critical realist analysis. All data were therefore thematically analysed with regard to:

- reflexivity by the researcher (incorporating a research diary kept throughout the process, supervision and literature);
- weak social constructivism, not taking pre-existing categories, language, models and theories at face value, but accepting that there is a material reality that is interpreted in the interplay between power, language and/or social actions consistent with a critical realist epistemology;
- previous theoretical and empirical findings in relation to the capabilities approach;
- concepts pertinent to social perspectives of mental distress;
- within a critical realist epistemology seeking interpretation of findings that considers the empirical, actual and real layers.

Bias is inherent in qualitative social research, and therefore is written in to the analysis, following Spencer (2003, p.14).

## **4.7 Quality in qualitative research**

Spencer et al (2003, p.7, n.1) note that in qualitative research:

there are no 'validated' instruments or standardised methods, which means that quality cannot be assumed on the basis that certain methods have been used, but must be demonstrated in each case.

They posit four central principles for quality in qualitative research (2003, p.7): contributory to knowledge, including theory; defensible in design to answer the questions posed; rigour in conduct, systematic and transparent; and credible in claim, making plausible arguments about the evidence generated. These should be assessed through evaluating the credibility of interpretation and inference made in the findings; the research process (design, sampling, data collection, analysis and reporting); and research conduct (reflexivity and clarity of underpinning assumptions and values, reporting of ethics, and auditability).

This study seeks evaluation using these principles in combination with Tew et al's (2006) value base for social research. The application of Spencer et al's

central principles unfold in the various chapters of the study, in addition to the explication of the methodology reflexively analysed in this chapter.

Tew et al's (2006) values were addressed through the study as follows.

Partnership was addressed through discussing the research focus and fieldwork approach with voluntary organisations; being clear with them and participants about my ontological position towards the understanding of people with mental distress and my epistemological position of validating experiential knowledge; and having a two-stage research process enabling reflection by participants on their first interview responses. Standpoints and distance were enabled through allowing participants the opportunity to interpret their distress experiences in their own way as valid and coherent, with the potential to challenge dominant understandings. However, as 'raw experience does not immediately turn itself into useful knowledge' (Tew et al, 2006, p.11), these standpoints were interpreted using sociological theory critical of reductionism in framing understanding of mental distress. Holism not reductionism was attempted by framing the unit of study to be the whole life, not diagnosis or 'symptoms', bringing in the social determinants, circumstances and consequences surrounding mental distress and experience of the psychiatric system. Diversity was incorporated by assuming that whilst participants' experiences would be unique, they may follow certain sociologically established patterns, for example as seen in the macro-level data, and by applying social and geographical inferential caution. Emancipatory purpose was sought by enabling participants to potentially gain more awareness of their social justice situation through participation in a normative study, explicitly achieved in some cases (e.g. Arthur, see section 8.2, and Caroline); and through proposing to report the findings of the study in accessible language to participants and recruiting organisations, producing 'evidence and theory that can enable service users ... to ... challenge stigma, injustice and social exclusion' (Tew et al, 2006, p.17).

In relation to emancipatory purpose, the ethical position taken in this study was to tell prospective participants that this was 'pure research' using a model that was interested in achieving social justice, but that findings could not be predicted. Several participants wished to take part in order to 'help others', but I was very clear that we would not know whether, how or who the results might 'help'. No participants declined participation after this discussion, which could

indicate that the explanation aided understanding of the purpose and ethics of social science studies, but could also reflect the power of the researcher.

These values could have been more fully achieved by working explicitly with people with experience of psychiatric hospital when formulating the Ph.D. proposal and research questions, and involving this group in fieldwork and data analysis. However, understanding the potential benefit of using capabilities required in itself prior knowledge of capabilities literature, just as inpatient understanding of the psychiatric system required in itself experience which I did not have.

## 4.8 Conclusion

This chapter has reflexively explained the underpinning values and principles of this qualitative study alongside the choices made in terms of the practicality of conducting the research. By investigating empirical outcomes at micro-levels, as Zimmerman (2006, p.481) suggests, and as this study does, a picture of wellbeing and freedom in a particular population can develop. The real-world complexity drawn out by Zimmerman (2006), bridging sociology and capabilities, is reflected in the study, drawing out and interpreting which capabilities and functionings may have been experienced and may be valued by people over time and in different relational contexts, influenced by structure. The study thus incorporates changes over time, 'opening up' the analytical, formal and substantive promise of capabilities through the application of sociological theory and methods. It achieves this through critical realist ontology, an interpretivist epistemology, and analysis of the social justice experiences of a purposive sample of people with mental distress from a single administrative area with recent experience of psychiatric hospital, using a combination of inductive and deductive methods drawn from previous capabilities studies of populations experiencing mental distress or social injustice. The study is 'an ongoing dialogue between theoretical concerns and empirical evidence' (Esterberg, 2002, pp.8-9), and offers a balance of partnership and distance (Tew et al, 2006). The research design seeks to demonstrate ways in which capabilities concepts (agency, structure, diversity, functionings, capabilities, Conversion Factors, adaptive preferences, thresholds and domains), may be being enacted, extended or contradicted in the lives of people with mental distress.

In-depth sociological study has not been found to be conducted with this population group using Tew et al's value base for mental health research (2006), explicit critical realism and a capabilities framework for analysis. The evidence suggests that this may be of value for both understanding the social justice experiences of people with mental distress, and for testing the limits of the capabilities approach. Thus the study becomes a critical qualitative exploration of the lived experience of mental distress using concepts from the capabilities approach, and also a critical exploration of the capabilities approach through lived experiences of mental distress.

Sociological analysis of the lived experiences of people with mental distress in Glasgow with recent experience of psychiatric hospital using a capabilities framework has the potential to draw out a particular conceptual understanding of the social justice of participants. First, the analysis highlights what *is* in terms of social justice, and through applying capabilities open up a way of understanding what *ought* to be, evaluation implicit in the critique (Sayer, 2009, pp.776-777). Second, it can demonstrate how the lives of people with mental distress conceptualised using the capabilities approach compare with other analyses made using concepts from social perspectives of mental distress. Third, by focusing on a social group that are not 'news makers' and considering broad aspects of social justice, the research may, as Silverman puts it, reveal 'the remarkable in the mundane' (2007, p.16); the study may discover new explanations whilst highlighting a social issue that is pertinent *because it is* neglected. Fourth, the study may update that of Barham and Hayward (1991) in terms of considering the predicament of living with mental distress and the injustices that they found, providing a commentary on the impact of contemporary policy and practice towards this population group, including the MHA 2003, recovery, community care and anti-stigma campaigns. Fifth through taking a critical realist approach to the analysis, interpretation of data using underlying explanatory layers shall take the analysis beyond the empirical. Sixth, it may induce substantive theory about the social justice experiences of people with mental distress.

The character of the data chapters is a mix of both overarching cross-case themes that describe pertinent aspects of social justice experiences, and within-case examples of aspects of social justice experiences that are pertinent to the



individual and not generalisable to the sample (ref. Emmel and Hughes, 2009). These are written up using interview quotations, with analysis drawing on reflexivity, weak social constructivism, critical analysis of capabilities approach concepts and social perspective concepts, within a critical realist ontology. Chapters five, six and seven include data from the stage one interviews and the 'update' conversations at the start of the stage two interviews; chapter eight focuses on responses to the domains diagram. The characteristics of thriving, surviving and 'being outside', as described at the end of Chapter one, emerge throughout.

## 5 Living with mental distress

### 5.1 Introduction

...so I was getting to a stage, maybe four or five weeks in, where I was half at home and half in the hospital and it was a gentle reintroduction back into the big bad world outside that had caused me to be ill in the first place. (Steve)

We have seen that the sociology of mental distress has long explored the relationship between the materiality and the social construction of mental distress and posed questions about the social or biomedical determinants of the experience (chapter two). All participants in the study described their experience of mental distress as being subjectively material emotional feelings, not as a pure social construction for which they had received a label or been hospitalised with no relation to an internal set of emotions. However, this did not mean that they interpreted their experiences as simply medical or biochemical. Subjective experiences of mental distress were heterogeneous, and whilst they led some people to the extremes of attempting suicide, there were also, for some, positive experiences. In capabilities terms, this chapter describes how subjective mental distress as a personal Conversion Factor, yet socially determined, particularly disrupted agency. Data on suicidal and self-harming thoughts and actions then demonstrates the interplay between personal and social Conversion Factors.

### 5.2 Predispositions and precipitants of subjective mental distress

19 of the 22 interviewees discussed their perception of the cause of their subjective distress. These were volunteered, demonstrating the salience of this issue to participants. Some spoke about cause specifically in relation to a precipitant for their mental distress experience leading to hospitalisation; others referred to the issue that for them explained the *context* of the experience, or a predisposition to wider experiences of mental distress. Others crossed both categories. Several participants had experienced mental distress for many years prior to the specific experience that resulted in their first hospital admission. Whether talking about predisposition or precipitation, social determinants of mental distress (Tew 2011, chapter three; WHO and Calouste Gulbenkian

Foundation, 2014) dominated the data, in particular childhood and family relations and work relations, but also more complex social mixtures. Minority explanations were linked to physical health and onset related to substance abuse.

Family relations formed the largest corpus of perceptions of social determinants of subjective distress leading to hospitalisation. Deaths of parents were precipitants for Barbara and Robert, who already had complex lives including learning disability and addiction respectively. Fiona's daughter committed suicide; she then tried to kill herself, was hospitalised and was subsequently diagnosed with manic depression (her term). Lara and Ivy each indicated childhood abuse as an underlying cause. Harry linked his causation to family context: genetic, incident-stimulated or both, reflecting the non-determinism of explanation of determinants (Tew 2011, ch.3; Venkatapuram, 2011):

I: So the psychologists you were seeing was helpful in terms of...

R: ...trying to work out where this all comes from, er, identified an event when I was about seven years old that probably triggered it, but if we go back into family history then it was fairly inevitable that I was going to have mental health problems if as people seem to say, it's genetic.

Caroline saw a lot of mental distress in her family, but identified her ex-partner as having a precipitating role: *'he kind of kept me in a bit of a sick role... I'm glad that I gave him the old heave-ho ... things have improved a lot since he's been gone'*. Whilst Caroline used her agency to change her situation, Harry's model implies that the structural and social explained his onset and so constrained his agency to change his situation.

Stresses at work or in wider life were a precipitant of mental distress for some, for example Sophie, who hinted at prior insight, knowing *'things were bad'*:

...it was like 'no wonder I was unwell' because I was working, I was volunteering at three different places, I was in a band, I was doing too much. I knew things were bad so I was just trying to fill up my life...

Both Harry and Gary had been on antidepressants for a decade before they experienced more serious mental distress, leading to hospital. Gary was in a

factory job he hated, with little wellbeing, but little agency to change his position. Harry ran his own business working round the clock:

...although it was the October when I went into hospital, I was beginning to think there was something wrong earlier in the year ... I was beginning to have somebody sitting on my shoulder telling me what to say. I ... was beginning to hear voices.

Steve had previously experienced mild depression. He thought his distress experience would retrace the previous path, but this time his overwork precipitated something more serious:

I couldn't go on driving myself ... I was just caught up in that whole thing ... neglected my own health and my family ... and it all came crashing down...

So precipitants of subjective mental distress leading to hospital could be the culmination of social stresses which the individual may recognise but lack the agency to change, in capabilities terms, the structural and social dominating personal Conversion Factors.

Tim and Jon had multi-layered explanations for their subjective distress. Jon's grandfather experienced mental distress, but *'life experience and drugs has brought it out. I'm unfortunate to get an illness. Maybe with more guidance ... I would have been alright'*. He had a breakdown aged 21 triggered by a mix of factors including taking illegal drugs, living in a flat in which he felt vulnerable, and having a threatening neighbour. Tim also described a mix of predisposing factors, giving him *'kind of depression episodes'* until a precipitant for more serious mental distress happened:

I broke up with my son's mother, that wasn't the reason why I became ill ... but it was ... the catalyst... [G]rowing up in Northern Ireland in the 70s and 80s was quite tough... I lost my mum and dad within eleven months ... I lost friends who had been murdered...

Two participants explained that their subjective mental distress had emerged as a result of physical health problems. Becky experienced colitis which led to her feeling weak and low, and was given steroid treatment, a reaction to which made her feel high. She was diagnosed with depression and a manic episode. Francine had a first experience of depression which she linked to *'post-glandular*

*fever, and it was relatively short, self-contained, went away and it was fine’.* As with Steve, she wrongly assumed that her second experience would follow the same path, but it lasted, resulting in her being in hospital and leaving her job.

Jack’s onset was precipitated by drug abuse at Glastonbury Festival:

...I took so much psychoactive chemicals that I basically completely went psychotic for days and I ended up getting Sectioned ... they kept me for a few days, medicated me and then sent me back up the road with a travel warrant...

So whilst explanations are always partial, these views of predisposition to and precipitation of subjective mental distress demonstrate how people theorise or explain in ways which make personal sense. The explanations group into those which are socially engendered and complex, or which are linked more directly to physical experiences of illness, or medication. There is some overlap between the two groups. These suggest that subjective mental distress is a material experience involving a range of atypical emotions, and supports the literature and epidemiology on social determinants of mental distress, summarised as ‘Certain population subgroups are at higher risk of mental disorders because of greater exposure and vulnerability to unfavourable social, economic, and environmental circumstances’ (WHO and Calouste Gulbenkian Foundation, 2014, p.9).

In capabilities terms, subjective mental distress was commonly experienced as predisposed or precipitated by gaps in the achievement of other important dimensions of social justice, which can be summed up using Nussbaum’s (2006) domains, for example, lack of physical security (e.g. violence and abuse), lack of a comfortable standard of living, an unbalanced engagement in productive and valued activities, or an insecure individual, family and social life. Capabilities provides a different way of conceptualising the determinants of mental distress, demonstrating the complex way in which the lack of particular domains could heighten risk of an intense negative outcome in the health domain, the loss of which may in turn have an impact on both the predisposing or precipitating domains and other domains. This provides a more complete version of Tew’s ‘triple whammy’ argument (2011, pp.104-105), following more strongly Wolff and deShalit’s analysis of corrosive disadvantages (2007). It is not only Tew’s

process of: precipitants - risk of distress - stigmatisation - intensification of distress; rather, it is predispositions and precipitants (i.e. loss of some capabilities domains and so social justice) - risk of distress - risk of further losses in the same and other domains - intensification of distress and further loss of social justice.

In sociological terms the ways in which those predisposing and precipitating social experiences were themselves shaped can only be explained by wider factors than the role of the dominant psychiatric system focused on by much of the sociology of mental distress, suggesting the need for a critical realist approach to the data, bringing in structural levels from which capabilities has also tended to shy away.

### **5.3 The feeling of experiencing mental distress**

Participants described how it feels to experience mental distress - the range of atypical emotions for which they had sought voluntarily or had enforced psychiatric treatment. They related a range of atypical emotions, including listlessness, 'depression', 'anxiety', extreme happiness, disassociation, seeing visions and hearing voices. When talking about their mental distress, some participants noted that they did not remember the 'highs', but remembered the 'lows' (e.g. Lawrence, Fiona), revealing the potential for gaps in the data, but also evidencing that participants were able to be accurate in their descriptions. Almost all participants said that mental distress or iatrogenic effects could strongly reduce agency, constraining what they could do, but this could be hard to distinguish, for example whether sleeping and listlessness were effects of medication or mental distress for Arthur, Bridget and Francine.

This section focuses on what people said about how subjective mental distress affected them, the material feelings not always included in medical model-based studies that tend towards objectification and classification, or in survivor-influenced studies that focus on the psychiatric system. The section aims to implement the principle of 'standpoints and distance - combining the experientially based knowledge of service users with rigorous analysis' (Tew et al, 2006, p.vi). It focuses less on the barriers, determinants and experiences of discrimination and prejudice related elsewhere in the study. The experiences

divide into those that are characterised below as feeling ‘depressed’, ‘anxious’ and related feelings; feeling ‘high’; a range of experiences collected under the term ‘psychoses’, such as disassociation, hearing voices and other hallucinatory experiences; and other, less categorisable experiences of mental distress. The data demonstrate the overlaps between and the individuality within these categories, this partiality reinforcing the critiques of categorical clinical diagnosis. In capabilities terms the data identify ways in which these feelings impacted particularly on agency, following Tew (2011, p.29), which in turn affects what participants can do and be, or their social justice, when experiencing these atypical feelings.

### 5.3.1 ‘Depression’, ‘anxiety’ and related feelings

Participants described needing to sleep for very long hours, not wanting to see people (e.g. Lawrence, Francine, Robert), not being able to concentrate (e.g. Sophie, Kirsty), and listlessness, for example Kirsty: *‘Most of the time I was just sort of catatonic, like I would just stare at the wall ... it was just really debilitating’*. These feelings could sometimes continue for years. Losing hope could also be a dominant internal feeling, such as for Lara:

After I lost a friend to suicide in 2009 I had a really, really bad depression for a long time, I just couldn’t see any, any light or any hope at all...

Steve was similarly hopeless in the period prior to his hospitalisation, and described the internal feeling of his mental distress:

...the pain, or blackness ... like a wave coming from the distance in the ocean, and then coming and building and building ... til it’s like a huge wave at the shore. And the only way I could get that wave to stop was to get a picture of me putting a gun into my mouth and pulling the trigger... [T]he wave would subside, and then it would start again out in the ocean and come towards me.

When in hospital, the character of his mental distress changed, he *‘felt someone had taken my brain out of my head and put it behind my back, where I couldn’t get it...’* He couldn’t read, watch a TV programme, *‘I’d almost lost the power of my voice’*.

A tension emerged between Kirsty's sense that her depression could benefit her creativity and the reality that it was actually not so helpful:

...I had this idea in my head of this ... 'tragic genius' (laughs), after Sylvia Plath I read lots of other depressed poets and writers ... I thought that you couldn't ever have anything meaningful to say unless you're really depressed? ... I thought if I get better then I'm somehow going to, be shallow... I don't know why I thought I could be more creative if I was depressed, because ... the opposite was true...

Kirsty's mental distress was in conflict with her agency, her functionings being restricted as a result. She also illustrates how mental distress is not generalisable but constitutes a set of feelings that interact with the lives of unique human beings: the quiddity of experience.

Robert was unable to resolve his anxiety and depression even with combined medical, social and psychological supports - Conversion Factors in capabilities terms - and described the frustration of this:

The most frustrating thing in my life ... is not being able to beat anxiety and depression, ... because you're basically up and down like that [\*clicks fingers\*], wee simple things that probably wouldn't bother anybody it bothers me... If somebody could give me a fix and say 'well, that's you beat it', it'd be like winning the lottery. My own GP says you can't beat it, just manage it... The psychologist also says it... I've done loads of counselling, I've done everything possible to beat it and I can't.

So, participants feeling low experienced suicidality, hopelessness, sadness and listlessness; feelings which could be ongoing. In themselves these feelings would disrupt their sense of individual agency, reinforcing both Tew (2011) and Sen's (1993) tension between agency and wellbeing, impacting on their ability to do and be things that they had reason to value, and so on their social justice.

### **5.3.2 Feeling 'high'**

Jon described how feeling 'high' helped him to be artistically productive, which he found helpful for managing his mental distress. He also needed to be alert to others' warnings that he was being too prodigious, and he knew that the absence of warning comments meant that he was in equilibrium:



...you've got this thing about bipolar that they can do ten things ... I've got about ten paintings on the go ... but ... you can do too much ... a lot of people are telling you you're doing too much. So if you can identify and take on what they're saying you're doing well. [I]n the past that used to go over my head, so the less people are telling me that now, I must be doing something right.

Although no participants experienced feeling 'high' as an unmitigated pleasure, some vividly described the wonder that could be sensed, such as Becky who had what she described as a psychotic episode involving euphoric effects after being prescribed high-dose steroid treatment for a physical illness:

...it was so intense ... every moment, every movement, every colour is infused with meaning... like ... a car accident and this massive adrenaline rush, it's like that, but every day, every moment is like that... it's incredible.

She described the benefit of her distress experience: *'my experiences, they were exactly what I kind of wanted or value, kind of intense experiences that seem kind of drenched in meaning...'* But although this mental distress gave her thrill, joy and wonder, upsetting dreams and exhaustion happened too:

I would have horrific nightmares of people being murdered, loads of blood everywhere... And then suddenly it was just too much, my brain was reeling and I basically had to lie in my room in the dark... My mind was just like a rollercoaster and it was not pleasant...

Lawrence described feeling more lucid and sharp when high, and also of achieving a spiritual understanding which had been inaccessible to him outside his experience of being high. This continued to influence him today, comparable to Becky's thrill in entering an intense new world:

...that time I much enjoyed the experience of being ill... the first time it had been quite scary and new, but I stayed high for a lot longer and quite enjoyed as I saw mind expanding ...

He described how being sectioned and in hospital could provide a safe space for mental exploration when 'high', enabling the dominant norms of social conduct to be expanded in a way that would be challenging in the outside world, explored further in chapter eight. This reinforces survivor-influenced literature relating to the lack of social value placed on experiences of mental distress due to dominant social norms. Lawrence and Becky are describing characteristics of

‘being outside’, of experiencing through mental distress feelings that were beyond dominant norms of human experience, and that provided them with personally meaningful insights which form an ongoing part of their lives.

But Lawrence, and Lara and Monica too, also described risky behaviours driven by feeling high, and which they did not relish. Monica almost got into fights, Lawrence left work abruptly. Lara found herself in high risk sexual encounters and described the difficult consequences of being high, in the context of her fluctuating mental distress:

...I feel like I lose control when I’m high. At least when I’m down I know what I’m doing, but when I’m up it just happens? And I find that very difficult to deal with ... when I come back down ... I’ve got to deal with the consequences of what I did...

So, feeling ‘high’ had a disruptive impact on individuals’ sense of agency which could lead to both positive and negative experiences, outside dominant norms of human experience. When positive the experience could be held onto and become a potential part of creating a personally valued - if not socially valued (Hopper, 2007, p.874) - capability set.

### **5.3.3 Hearing voices and other hallucinatory experiences, or ‘psychoses’**

Participants described a variety of material experiences, broadly characterised as ‘psychoses’. Participants heard voices that disrupted their agency, for example Harry at work: *‘I was ... beginning to have somebody sitting on my shoulder telling me what to say. I ... was beginning to hear voices’*. Arthur thought that people could hear his thoughts, hearing voices *‘mixing me up... telling me to do things’*. Bridget had heard voices and seen terrifying visions since she was twelve years old: *‘Sometimes I’ve horrible hallucinations like, at one point I seen myself hanging...’* and *‘I remember looking in the mirror and it all changed and it was the devil and he says ... ‘if you don’t kill yourself I’ll kill your child’*’. Tim also experienced voices and the devil during what he termed ‘flare ups’ of ‘psychosis’, describing the impact on his agency in an act of citizenship:

...I got a letter ... about being on the jury ... and I thought it was from the devil, I thought the devil wanted me to go there just so that they could find out more about me... I thought 'what are you talking about Tim, this is silly.' I took it to [NAME] from [mental health voluntary organisation] and she reassured me... But it's keeping that guard up because the words from the devil they were trying to get into my head... it's quite exhausting...

Lara described an example of her mental distress as having '*slightly delusional ideas*', her 'high' becoming a 'psychotic' experience:

...I thought that if I made eye contact with people they could read my thoughts. I thought that there were protective spirits who wanted me to get pregnant because I was going to have a special child... important to the world...

Monica described depression and psychotic experiences intermingling:

I know that I get very, very depressed... and I know that I've psychotic symptoms because I hear voices and sometimes I see things and sometimes I smell things that aren't going on, and sometimes my thinking isn't as rational as it would be just now.

Bridget exemplified how post-natal psychosis affected her, jeopardising her life: '*because I thought I could fly I tried to jump off the veranda and my sister just managed to grab me ... or I'd have been away*'. Sophie specified how her psychosis felt, disrupting her agency to do and be what she wanted in several ways:

...I cut all my hair off, shaved my eyebrows, plucked out my eyelashes and put pins in my face ... I heard voices and I got really bizarre ideas and I kept seeing things... I was really paranoid. I didn't use the subway for 18 months because I thought it was going to get blown up. Just the usual run-of-the-mill psychosis! (laughs)

Arthur related how, whilst negative voices also reduced his substantive freedoms to do and be what he wanted, he had used his agency to create positive voices to help himself: '*I've created this doctor voice ... that will help me out and take the other voices away*'. So, agency could be used to engage psychosis with itself, with the ultimate aim of reducing the psychotic experience, reflecting one of the major contributions of the user movement to managing voices (Romme and Escher, 1993).

So psychotic experiences were diverse, and sometimes terrifying or burdensome. They disrupted individuals' sense of agency as they led to participants misunderstanding situations or taking actions that they would not have otherwise taken. Whilst these experiences were outside dominant social norms, unlike some of the experiences of being 'high' there was not a sense from participants that these experiences offered personally valued insights. Instead they become experiences that disrupted peoples' agency to be able to shape a valued capability set.

### 5.3.4 Other feelings of mental distress

Several participants had feelings of mental distress, or experiences that did not fit the above categories. These continued to be feelings within the self which disrupted their sense of agency. Jack described a characteristic of his mental distress, diagnosed for him at that point as 'personality disorder', as extreme fear, affecting his ability to live in peace at home, comparable to Sophie's 'psychotic' anxiety:

I was usually boiling a kettle of water and, steak knives down my belt, and crouching close to my front door because I could hear them coming, I was just ... not well... I had this whole persecution thing going on about ... either getting marked out as a sex offender or a grass ... that's the worst end of a personality disorder as I've experienced it...

Harry's mental distress stopped him leaving the house:

[S]omeone once asked me to describe how this was and I photoshopped a couple of photographs of our front door from the inside and what this ended up like was the front door, no handle on the inside... but if you looked at the reflections in the pictures in the hall either side of it... the door was open. So, even if the door was open it was shut to me...

Harry had left hospital over five years previously, had experienced psychology, counselling, medication, outreach support and more, and still experienced these internal feelings. These social Conversion Factors had not changed his internal experience, similarly to Robert earlier. In his pre-distress life Harry loved the great outdoors, now the material impact of his mental distress frustrated his agency to do and be what he wanted:

Not being able to get out when I want to. Doing the things I want to do and which I know I can't do. I used to love hillwalking ... going into the wild places... One of my fantasies is to get a boat [but] I'd never go on it... I used to love travelling...

Harry's comment rounds up these accounts by participants of how the experience of mental distress as a socially determined personal Conversion Factor disrupted individuals' sense of agency in multiple ways, supporting Tew's (2011, p.29) thesis. The feelings were overwhelmingly problematic and unwanted. Only some feelings of being 'high' became a valued transgression of dominant social norms and informed an ongoing, wider capability set, a characteristic of 'being outside'. The data demonstrate that for this sample of people with experience of psychiatric hospital, mental distress is neither benign nor a social construction, but nor do people explain it in simple biomedical terms. In capabilities terms, the data suggest that subjective mental distress, whilst having a variety of predispositions and precipitants, can be conceptualised as a personal Conversion Factor, having a disruptive impact on individuals' sense of agency, so impacting, generally negatively, on what people are able to be and do. This could be to the point of self-harm and attempting to end life, as the next section describes.

## 5.4 Suicidal feelings and self-harming actions

I spent a considerable amount of time between seventeen and nineteen trying anything and everything I could to end my life. (Lara)

There's been times that I've attempted suicide. One time I was very, very close and the devastation when I woke up in hospital, the devastation that I actually woke up... was beyond anything that I could ever try to describe. (Caroline)

Chapter two showed that whilst suicide is far from confined to those with a diagnosis of mental distress, psychiatric populations are more prone to suicide than the general population. As one of the few studies applying capabilities to mental distress and suicidal behaviour notes, capabilities is helpful for conceptualising social justice for people in this context as it 'emphasizes the importance of determining the life dimensions most valued by people with lived experience - here, of coping with suicidal thoughts' (Alexander et al, 2009, p.1217). How Conversion Factors work together can help to explain how

structural, social and personal dimensions shape how peoples' agency is structured as they navigate the predicament of suicidal feelings. Thus, capabilities offers a means of framing what people with suicidal feelings find helpful for maintaining life and therefore for gaining the opportunity to live and potentially to experience social justice, bringing in the normative dimension of capabilities and critical social science (Sayer, 2009).

Sixteen of 22 participants talked about feeling suicidal and nine of these talked specifically about attempting suicide, some on numerous occasions. Some participants talked about their experiences in considerable depth, and often with ambiguity between suicidal feelings and actions, and self-harm, typified in Lara's description:

...when I first left [hospital], I was overdosing probably at least once a month ... self-harming up to every day ... I was really struggling a lot of the time? And while now my mood still swings quite a lot, I cope with that better... In the last year I've overdosed once ... my self-harm's maybe been about three times in the last eighteen months ... again an improvement ... I used to have to get stitches all the time... I last a lot longer at home now with my worst depression than I ever did before without hurting myself...? [T]he problem is that I'm still getting that depression.

For this reason the presentation of the data avoids presuming simple delineation between these categories, avoiding the risk of overinterpretation or invalid conflation (De Leo, 2009, p.142) and respecting 'the experientially based knowledge of service users' (Tew et al, 2006, p.vi).

#### **5.4.1 Suicidal feelings, self-harming actions and agency**

For some participants, hearing voices and seeing visions could lead to confusion or fear, precipitating suicide attempts. Bridget had been tormented by voices and visions threatening both her and her daughter for decades. She had attempted suicide in many dramatic ways, for example once when in hospital:

I remember looking in the mirror and it all changed and it was the devil and he says to me 'if you don't kill yourself I'll kill your child'... [N]inety-nine percent of mothers would say 'I'll go instead of you'. So I ... cut my throat and it was all spouting out, there was people screaming and that and I woke up and they were stapling my throat. But see when you're ill though you can be really, really devious. Because I remember saying to

myself I need a backup plan there in case I don't die. So I had an open razor blade and I put it down my underwear and ... I remember saying to myself '...I'm going to heaven or hell who'll ever have me' and I ... fucked it again... I got fourteen staples, ten stitches and a transfusion...

Her agency had been shaped by hallucination, acting as a personal Conversion Factor, with medical staff as social Conversion Factors preventing her death.

Some participants felt or acted suicidally after experiencing stressful life events, demonstrating the precipitating role of negative social Conversion Factors. Steve had cumulative work stress that resulted in him envisaging shooting himself. Robert's mother died with complicated consequences, and as he *'didn't see anything better for us'* at that point, he overdosed on Ibuprofen and alcohol, expecting to die. After her daughter died, Fiona *'overdosed a hundred paracetamol ... [T]hinking that would do me'*. Capabilities analyses tend to skirt around the unavoidable personal tragedies of life, such as those of Robert and Fiona, focusing instead on those which are socially 'remediable' (Sen, 2010), such as discrimination or poverty. But personal tragedies also have a material impact on social justice. These data suggest how traumatic events may affect the emotions, and may then precipitate agency to end life, creating a further personal tragedy to be coped with by others.

Jack was polyaddicted and looking back saw himself as actively driving himself to an early death: *'I was just locked and lost and basically heading to a grave. I really tried hard to get to that grave, I really tried hard'*. Whilst he entered psychiatric hospital on three occasions, his suicidal actions were mixed in with his addiction. This entangling of addiction and mental distress in this context reflects Thornicroft's (2006, p.135) note that between one-third and two-thirds of people with psychotic disorders misuse substances, a marginalised group in both recovery and survivor-influenced narratives.

Some suicidal feelings were precipitated by stopping taking psychiatric medication perceived as non-effective, and in one case by the iatrogenic effects of medication. Gary had years on an antidepressant that he believed didn't improve his mood significantly. He stopped taking them and shortly afterwards violently attempted suicide. In these cases increased agency might again have

enabled negotiation of a different solution. Kirsty explained that she felt suicidal due to Seroxat, a 'new generation' SSRI antidepressant:

...there was a big controversy about that a couple of years ago, causing a lot of people to feel suicidal and that was definitely my experience of it, it was just an awful, awful medication, by far the worst one I'd ever been on.

This outcome was wrought by the way psychiatry, the mental health system and social-structural dominant norms of medicalisation of mental distress can lead to the prescription of psychiatric medication with known problematic iatrogenic effects for young people.<sup>4</sup> Kirsty and Gary demonstrate the shaping of choices available to people with mental distress, identified by Plumb (2012) as making the concept of informed consent, which implies agency, meaningless.

As suggested, there is an ambiguity over agency at these profound moments of suicidal feelings and action. Bridget described lack of a sense of agency when discussing a past hallucination:

I: do you know that you want to kill yourself at those times or is that out of your control?

R: No it's just voices, aye it is, it's not in your control. It's not that you want tae dae it, it's what they're telling you tae dae, whilst you're hallucinating you see yourself like dead and whatever, cutting your wrists or whatever.

Tim described a greater tension in a context without hallucinations:

...I could see [and] feel myself walking into the kitchen to get a knife to slit my wrist ... inside I was screaming 'what are you doing? Don't do this. What's wrong with you Tim?' ...[N]o matter how hard I tried to stop myself from walking in there I couldn't, it was almost as if I was programmed to do it, I was just like a puppet ... So sometimes I knew what I was doing, other times I didn't. Sometimes I wanted to just sort of hurt myself, other times I wanted to kill myself.

For Bridget the power of the hallucinations almost entirely removed her agency. Tim had insight into what was happening but his agency was disrupted and fragile.

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<sup>4</sup> See [www.sehd.scot.nhs.uk/publications/DC20030610Seroxat.pdf](http://www.sehd.scot.nhs.uk/publications/DC20030610Seroxat.pdf), sourced 31 March 2015.



Suicidal feelings and actions put the very existence of the self in jeopardy, a precursor to being able to develop a capability set, achieve functionings and to have the opportunity to live with social justice. These examples inform empirical evidence of some of the consequences of having very little agency to counter suicidal feelings. For some, suicidal feeling or action was precipitated by subjective mental distress, a negative personal Conversion Factor, sometimes combined with addiction, which became overwhelming, powerfully disrupting personal agency. For a second group the precipitant was more firmly driven by negative social Conversion Factors - a change in social context, such as overwork, death of others, separation, medicinal underefficacy or iatrogenic effects - to which suicidal agency was a disrupted response. For all these groups, their social justice was undermined in an extreme way.

#### **5.4.2 The mitigation of suicidal and self-harming feelings**

Participants talked about a vast array of interventions that mitigated the functioning of suicidal and self-harming feelings and actions, replacing them with alternative functionings. If suicidal feelings and actions are conceptualised as the result of negative personal or social Conversion Factors, these interventions can be conceptualised as positive social Conversion Factors.

Lara listed interventions developed with mental health professionals, acting as social Conversion Factors, which helped her to develop the agency to move from the functioning of self-harm and suicidal thoughts to the capability of living perhaps with, and perhaps beyond these feelings. These included achieving routine, seeing people, organising distractions to thoughts of self-harm when she was on her own, and having a safety plan:

So if I'm wanting to calm down there's a section on my safety plan that says 'for calm - go for a bubble bath with lavender and candles...' [I]f I'm really struggling not to actually go and overdose or self-harm, then I've got ... 'housework and going out and doing things, meeting up with friends...' [laughs] ... getting busy doing something.

These desisting activities are a list of alternative functionings to self-harming or suicidal actions, enabling Lara to regain agency over her mental distress and so enact the functioning to live. They demonstrate how capabilities can be

operationalised to focus on micro-level activities and enable conceptualisation of issues as significant as agency in the context of life and death.

In the immediate-term, services such as the mental health Crisis Team helped Gary, Lara and Bridget to stay alive when the motivation to die was at its strongest. Bridget had her life saved multiple times by nurses, as did Gary, Caroline, Lara and Robert. Medical interventions as social Conversion Factors maintained peoples' threshold functioning of life in the immediate term.

In the short- and medium-term, participants found combinations of social Conversion Factors helped to offset suicidal feelings. Tim found mental health-specific groups and drama therapy helpful. Steve changed his work-life balance, Tim and Monica reduced or stopped volunteering. Robert found supported accommodation made the biggest difference and, as with Jack, avoided situations in which he might be tempted back to addictive substances. Francine, living alone, found that her pets averted her suicidal actions, if not feelings:

As sad as this may sound for three little fuzzy things, they've made quite a big difference... I feel like I've got something to go home to. I feel as if I have a little responsibility for something. The couple of times that I've been really suicidal, one of the things that has pulled me back is 'who'll look after the gerbils if... if I [speaking slightly archly] top myself?'

Almost all participants with suicidal feelings already took psychiatric medication. So the findings demonstrate that psychiatric medication does not always act as a positive social Conversion Factor; indeed there is some evidence that suicidal feelings could be stimulated by particular medication and that people could spend long periods on ineffective medication with suicidal feeling remaining. This suggests that other social Conversion Factors beyond medication are important to offset suicidal thoughts and actions. The data also demonstrate the diversity of social Conversion Factors required, individual for each person, reinforcing the benefit of this capabilities principle in fully understanding the situation, and in proposing a normative response that may improve the possibility of upholding the life threshold, so offering the basis for surviving or thriving with more or less social justice.

## **5.5 Chapter conclusion: how living with subjective mental distress relates to social justice**

The chapter findings are reviewed and critically analysed in the discussion chapter, but the challenging character of this data for the capabilities approach requires observations at this stage.

These examples have demonstrated the diversity of emotional feelings that are subjective mental distress. The data has confirmed that sociology that seeks to respect lived experience cannot ignore the material reality of mental distress. However, when mental distress is described in this detail, it becomes epistemologically impossible to both respect lived experience (Tew et al, 2006) and to generalise about subjective mental distress, enabling critique of psychiatric categories and the dominant norms through which these are structured. These diverse experiences were described by participants as having predisposing and/or precipitating social causes, their subjective perceptions reflecting the literature on social determinants of mental distress (e.g. Tew 2011, ch.3) rather than biomedical literature, demonstrating autonomy from medical discourse and power.

This chapter has argued that subjective mental distress exists as a personal Conversion Factor, disrupting agency in a range of ways. For Tew (2011) the dominant experience is of agency being disrupted. Here, this experience could be occasionally positive, enabling insights that participants could not previously achieve, and breaching dominant social norms. More often they were negative, disrupting what people could do in very practical ways, and disrupting who participants could be, because of how their distress affected their feelings and behaviours. The data therefore suggest that subjective mental distress, as part of an individual's personal Conversion Factors, tends to constrain an individual's agency, functionings, capability set and so social justice. However, subjective mental distress does not in itself fully explain whether people would have characteristics of thriving, surviving or being outside; this requires the integration of further data, including on the wider social determinants of the experience of mental distress, and on social responses to lives with experience of mental distress.

The data also demonstrated how experiences of mental distress can disrupt agency to live, so threatening the capability for life. They have shown how social Conversion Factors can be negative, as predisposing or precipitating factors for suicidal feelings and actions, and positive, including supporting the capability for life. In capabilities terms, if feeling or acting suicidally is seen as a functioning, then extending life with or without suicidal feelings and actions is also a functioning, offering the potential for other capabilities to be enacted. In the data, Conversion Factors worked together to shape agency as participants navigated the predicament of suicidal feelings.

Data on suicidal feelings and actions, very little explored within the capabilities literature, offer four contributions to capabilities philosophy.

First, as Francine noted in relation to her own suicidal feelings (chapter eight): *‘as somebody pointed out once to me ‘it’s a very permanent solution to a temporary problem’*’ This reveals a paradox within capabilities analysis: the risk of assuming that short-term functionings and long-term functionings are in harmony. People with mental distress who attempt suicide are an archetypal group to demonstrate the harmful impact on personal social justice of short-term actions. Second, the data offers empirical support for the critique made by Wolff and DeShalit (2013) that, in order to secure social justice outcomes, the capabilities approach may in some circumstances need to measure social justice by functionings - the actual life lived - rather than capabilities. Third, capabilities holds an assumption that people adapt their preferences in order to justify an oppressed existence. The data show that people can feel for a variety of reasons that continuing to live is hopeless and choose to undermine their own wellbeing, and the capability of life. In this way mental distress offers a case-implication critique (Sen, 1980, p.197) providing a limit test for the concept of adaptive preferences.

Finally, Sen provides examples of ‘basic capabilities’ which include ‘the capability of escaping avoidable morbidity and premature mortality’ (1993, p.31). Self-harm and attempted suicide clearly breach these, as they also breach thresholds of Nussbaum’s domains of life and health (chapter eight). The data therefore provide an example of resonance between Sen and Nussbaum’s differing analyses, reflecting their shared normativity.

Whilst these experiences of emotional hurt expressed as subjective mental distress contribute to explanation of social justice outcomes, a less reductive analysis requires a wider explanation. An understanding of how resultant interactions with the mental health system contribute to social justice outcomes is also required, and it is these experiences to which the study now turns.

## 6 Living with the mental health system

### 6.1 Introduction

The sociology of mental distress demonstrated the significance placed on the role of the psychiatric system in the lives of people with mental distress. This chapter explores the impact of the mental health system on participants' subjective experience of mental distress and on their social justice. The mental health system includes hospitalisation, but also community and psychological treatment, diagnosis and medication, and the analysis includes the social norms and laws within which these are framed.

### 6.2 Hospital-related experiences, mental health law and their impacts on social justice

Collectively, participants recalled 49 periods in psychiatric hospital in their lives. Only four participants definitely had only a single admission; 11 had experienced three or more. The Mental Health (Care and Treatment) (Scotland) Act 2003 introduced Community-Based Compulsory Treatment Orders and was interpreted as ground-breaking with its 'voice, choice and rights dynamic' (Scottish Executive, 2004), bringing in rights and principles such as equality, participation, maximum benefit, least restrictive alternative, reciprocity, advance statements and advocacy, to guide 'how professionals should work when providing treatment and care under the Act' (Mental Welfare Commission for Scotland, 2014).<sup>5</sup> However, no participants referred to experience of Community-Based CTOs, with barely a mention of Compulsory Treatment Orders by name despite almost all talking intently about their experiences as a psychiatric inpatient and in relation to mental health professionals, and many talking about being 'Sectioned'. A small number of participants did mention advance statements or advocacy.

This sub-section analyses the contribution of psychiatric hospital-related experiences to shaping what people were able to do and be. It first describes participants' perceptions of the impact of admission, then of being an in-

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<sup>5</sup> At <http://www.mwscot.org.uk/the-law/mental-health-act/principles-of-the-act/>, sourced 04 February 2015.

patient, and finally of being discharged. The impact of the legal aspects on what people were able to do and be completes the sub-section.

### 6.2.1 Admission experiences

Participants commonly questioned the need for their admission to hospital at the time it happened, being more accepting of it in retrospect. This could lead to conflict with psychiatric services, for example Sophie and then Arthur:

I wasn't complying with the treatment so you can kind of understand it; they had my best interests at heart. I didn't see that at the time of course, I called them for everything.

See when I was ill Richard I didn't know what was wrong with me, I was shouting and bawling at people... so I can understand why the nurses did that, put me on a Section to go out with a nurse.

Fiona argued that the system needed to override her self-understanding as she could have gaps, especially when 'high': *'I go along with it. See when you're a manic depressive as I say you don't know the highs but you know the lows'*.

These participants are implying that it is correct in these situations that the MHA 2003 can overrule their consent, with compulsion superceding agency and so capabilities, determining their functionings. In doing this they exemplify Foucault's (1991) concept of governmentality, accepting the role of the state in restricting their freedom.

When participants attempted to resist admission, they generally had little agency to do so, with the exception of Becky who had a cousin working as a CPN who helped her negotiate treatment at home. This indicates how pre-mental distress social relations could influence relations with the mental health system. The potential for the MHA 2003 to override consent led to participants' agency being overridden, for example Sophie: *'I was told that we will Section you if you don't go into hospital. And then I tried to leave and they said we will Section you. I was coerced basically...'*

Lara expressed a dilemma between wanting and needing to be in hospital in the short-term, for example when she was unable to promise that she could resist attempting suicide:

R: ...and at that point they had to say 'listen, this is hospital now', ... if I'd been able to keep myself safe they'd have kept me at home, but I couldn't do it...

I: ...in those circumstances are you feeling that hospital is the place you want to be or not?

R: It's weird because it's not a place I want to be but sometimes I know I need to be there. [S]ometimes that's where I'm going to get the support I need ... and it gives me that chance to get my head together ... it's never somewhere I want to be, because it's not helpful in the long term.

Lara's preference not to be admitted was overridden by the structuring of the mental health system, which could not provide her with adequate support at home. Her plea is not that she does not have a material experience of mental distress requiring social support, but that the existing structures of support remove her ability to use agency or autonomy in how this support is configured, for example through a home-based model of support,<sup>6</sup> underscoring the critique of the ideological and practical limits of the system (chapter two). Viewing this sociologically and using a capabilities lens, the way in which both psychiatric decisions and concomitant support services are ideologically and practically structured (see MHA 2003 section, chapter one) mean that Lara's freedom to be supported within her home to manage her distress and maintain her life is deprived by dominant social norms. Her maintenance of threshold social justice is limited by the services available, which reflect the medical model, rebuffing her agency to choose the way in which she is supported to achieve the same outcome - maintain wellbeing and the functioning of life - and so restricting her capabilities.

### 6.2.2 In-patient experiences

Participants were very experienced in how it feels to be a psychiatric inpatient. Entering psychiatric hospital means living in a very constrained social environment, and subject to specific enacted or potential - as noted by Sophie above - constraints under the MHA 2003, reflecting whether admission is compulsory or voluntary.

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<sup>6</sup> Contrast with the Northern Finland Open Dialogue model, from Jaakko Seikkula [www.dialogicpractice.net/open-dialogue/about-open-dialogue/](http://www.dialogicpractice.net/open-dialogue/about-open-dialogue/), sourced 01 February 2015.



Some participants distinguished emergency and long-term hospital use. Several referred to the interventions of hospital staff to save their lives. This happened to Bridget on numerous occasions in hospital as voices and hallucinations encouraged her to kill herself. Steve noted: *'continual encouragement and support from the staff was the key aspect. Some of them angels in my view, saved my life'*. Thus constraining agency disrupted by subjective mental distress could enable life to continue.

In terms of ongoing inpatient treatment, Steve and Lawrence, with thriving characteristics, had positive reflections. Steve aiming to be a 'model patient', trusting to the system and using his agency within that to underpin their model of treatment which had several strands, both social and medical:

...their belief [in me] and my trust in them and trying to do what they told me, being a model patient, and the medicine, I guess, played a part, and all the activities ... the walking, the group sessions, the relaxation class ... I was determined to get better, and do everything they said...

It was not always so consensual. Two participants from non-thriving backgrounds, Bridget and Gary, described assaults by nurses. Bridget, who kept rabbits, described unprofessional treatment by a CPN in hospital:

...I was really unwell and ... I said to her 'can you get me oot o' here?' and she started laughing and she said 'what do you want me tae dae, lock you up wi' your rabbits?' ... I was raging ... I asked for a new nurse and the next morning she ... said 'Bridget I never said that, that must have been the voices' so that made me lose the plot... 'no' I says 'voices don't talk like that' ... I got a new nurse...

Bridget, as an expert in her own voices, avoided having her understanding of the situation manipulated by the nurse, demonstrating the risk of exploitation by professionals on psychiatric wards, but also some agency to resist this. Gary experienced distress as a result of being an inpatient:

...it was detrimental tae my health ... every day was a war wi' the nurses ... I just I hated every second o' that thing ... it didn't make me get well it just made me worse...

He demonstrated how inpatient care could transgress dignity:

...one night they changed my room ... I went in, into the toilet and the door handle was all covered in shite... the guy before us had diarrhoea, wiped his arse on the curtains ... I complained and I got all this 'for fuck's sake!'...

Some participants had been admitted to more than one hospital and made comparisons. Francine, who worked in the armed services, was not on Section, but felt underprotected by being able to go out without the apparent knowledge of the nurses. She described other ways in which the same hospital provided little active support for wellbeing, which she contrasted with a positive experience in another:

The only thing that came out of [name of Glasgow psychiatric unit] that was positive was the change of medication... The rest of it was utterly pointless... Just there wasn't anything. The nursing staff and the care assistants just didn't interact with you... I had stopped being able to read because I couldn't concentrate ... I could literally just sit at the jigsaw ... I'd feel a ... sense of achievement when I put one piece... But we weren't allowed to use that very often because one of the girls with schizophrenia used to go in and mess it up... I used to [go] for walks with one of the other M.o.D patients. And we could walk in and out without them even knowing where ... we'd gone... Conversely ... [in psychiatric unit in England] it was a much more holistic approach to things.

Her agency at this hospital was overstructured in a minor context (jigsaw) and then understructured in a significant way (being permitted to leave the hospital), placing her wellbeing at potential risk. Her experience suggests that psychiatric hospital practices could be hugely variable, so forming part of the explanation for the diverse experiences of participants.

Being in a confined place with other service users could threaten wellbeing. Gary described his experience:

...people wi' the drink in their rooms, the drugs, the pills, the hash... people walking about steaming ... It's like a jail ... [On IPCU] it was much o' the same but it just depended how many visitors ... because that's ... how the stuff gets in...

Spending time in a particular Glasgow psychiatric unit in an area of high social deprivation was described in grim terms. Jack compared it with his time in jail:

...[psychiatric unit name] was awful... [S]ome of the staff were horrible... Some of the patients ... should have been somewhere a bit more secure,

some people shouldn't have been there at all, some ... should have been in prison... It was a frightening place.

The same hospital was described by Sophie, bringing in a social context:

It was horrific, it's awful. It's not the fault of the people in there, they've grown up in a deprived area ... there was some quite scary people ... and a lot of violence... it was not conducive to getting better... Then I got moved to [name of other Glasgow psychiatric unit] which was posh by comparison (laughs)... There was a woman who played the harp... This is not like [Glasgow psychiatric unit in area of high social deprivation]!

In contrast, Steve's experience of another Glasgow psychiatric unit highlighted the social insight that could be gained from the experience of being on a ward, contributing to a change in his value system:

I was on the middle bed, and on my left hand side was a man found guilty of murder ... and on my right-hand side was a drug dealer, about to go to prison after being assessed for mental issues, because he'd been involved in a drive-by shooting ... And actually I felt safe between them... from a sort of preconceived middle class perception that murderers and drug dealers are the scum of the earth... that changes a lot of the perspectives you had on life...

But the evidence shows that in order to enable a feeling of safety there must be limits to behaviours by both staff and other patients, limits which were looser for other participants. These differing social relations can be conceptualised in capabilities terms as positive or negative social Conversion Factors.

Participants' experiences were not only about constraint and medication; some had talking therapy. Francine's psychiatrist took a talking approach, helping her to reconsider her capability set and change career:

...my psychiatrist ... had this sympathy towards ... more spiritual, holistic type ideas, instead of just plugging you full of drugs and sending you home, he would do a bit of work. And we ended up one day with ... the thought for me that I wanted to explore ministry again.

So therapy, acting as a positive social Conversion Factor, could provide perspective and enable agency.

Developing his and Lawrence's earlier evidence, Steve further explained why people had such differing inpatient experiences: it is about being on the right kind of ward, and also being the right kind of patient:

...the doctors and nurses helped me incredibly ... they said 'we'll get you better, it'll just take time'... And I would say 'but look at these guys... Last week they walked out in front of a lorry on the A77. They're getting out.' And they said 'that's because we can't really do much for them. We're keeping you in because we can make you better.'

This shows how Steve felt treated with an expectation of recovery, and thus the prospect of social justice. Others were not, and were, paradoxically discharged more quickly than him *'because we can't really do much for them'*.

Whilst Steve and Lawrence had positive experiences as inpatients, more participants had mixed experiences on the wards, justice and dignity being undermined in a place in which people had very little sense of agency, negative personal Conversion Factors being dominated by the social and structural. This varied by hospital, participants suggesting a relationship with staff behaviours as social Conversion Factors, and also the socio-economic background of other patients, a structural Conversion Factor. This suggests how agency and structure, shaped by Conversion Factors, mutually constitute inpatient life. Whilst in terms of the MHA 2003 hospitals formally treat mental disorders whilst providing protection to all equally, the data indicates that they can reflect wider social injustices that contribute in themselves to mental distress (WHO and Calouste Gulbenkian Foundation, 2014).

The data provides a glimpse of 'through the looking glass' worlds, in which inpatient experiences might be on the one hand, as Steve experienced, therapeutic and enlightening, facilitating the possibility of thriving; and as participants with surviving characteristics could experience, stressful and conflict-ridden, enabling the short-term continuation of the life threshold and therefore the potential for future social justice, but in the context of an experience that in itself contradicted dignity, physical security, agency and participation, core capabilities concepts. The abuse and fear experienced by some participants, and the intoxicated and insanitary atmosphere described exemplify the micro-level ways in which people can be survivors of the mental

health system as described in some of the survivor-influenced literature, not only in terms of the formal repression of agency by the state, but also in terms of daily interactions.

### 6.2.3 Discharge experiences

The data suggests that there were two types of discharge. First, discharge from hospital into an improved personal and social situation, providing an opportunity for enhancing capabilities. Second, being discharged into a similar set of functionings as prior to admission, or what might be termed 'continuing functioning' discharges. The evidence that only four participants admitted as inpatients had a single admission, with 11 with three or more admissions suggests that the system tended to discharge people into the same situation, without a rebalancing of personal, social and structural Conversion Factors to negotiate the world outside and achieve social justice. This suggests insufficient 'enhanced capability' discharges and too many 'continuing functioning' discharges, capabilities providing a new way of conceptualising the long-standing 'revolving door' question.

'Enhanced capability' discharges were perceived by participants to be dependent on good individual staff to facilitate and liaise with external agencies and change the social situation that had contributed to mental distress. Steve was offered counselling, and was on sick pay from his employer for months, before they in turn provided him a staggered return to work, again reinforcing the influence of being in a thriving position pre-mental distress. Lara's psychologist was pivotal in helping her transition into women-only supported accommodation, and Robert's social worker helped him transition from hospital to alcohol rehabilitation.

In terms of 'continuing functioning' discharges, Arthur hid that he was hearing disturbing voices, was discharged, then overdosed and was readmitted. He did not wish to say that he was hearing voices because his understanding of the role of psychiatrists was that he would risk being labeled 'mad' and put in the State Hospital. Gary argued that poor discharges can happen as patients will agree to anything in order to get out of hospital, regardless of their commitment: *'you say tae anybody getting oot o' the hospital you go 'yes I'll engage in a' these*

*things' and then when you get there you're like 'what is this?'*'' Arthur and Gary show with clarity how the dominant social ordering of psychiatry and the mental health system govern how people behave and respond to both mental distress and the system. The system shapes how people interpret experiences of mental distress, including as having terrifying consequences for personal freedom. When that freedom is removed, people can do what is easiest to regain it, contradicting notions of rational health care, and a driver for 'continuing functioning' discharges. In capabilities terms, this demonstrates how agency can be shaped by a desire to be compliant in order to escape an oppressive structure, and how expressing subjective mental distress can be repressed for fear of incarceration, again reinforcing survivor-influenced critiques of the positioning of experiences of mental distress in the world.

Almost all participants talked about how, after discharge, professionals supported them with formal situations that held potential threat to their functionings - such as renewing a bus pass or experiencing a Work Capability Assessment - by providing evidence of mental distress (e.g. Harry, Robert, Fiona). Professionals helped with medication-related problems (e.g. Becky's CPN helping her withdraw from medication without side-effects) and suicidal feelings (e.g. the Crisis Team visiting Gary and Lara). These examples show how professionals could act as positive social Conversion Factors in helping people with social justice.

#### **6.2.4 Compulsory detention, voluntary admission and mental health law**

Participants said little about their experiences of the MHA 2003, for example on tribunals, advocacy or on the legal dimensions of being compulsorily detained. For no participants to volunteer this 'voice, choice and rights' dimension of the Act reinforces evidence of its low salience amongst those for whom it was intended to have most benefit (Griesbach and Jordan, 2013). However, these data hold disproportionate significance as they exemplify whether participants had the capability of upholding their legal rights within the MHA 2003, and provide evidence about the wider role of the law in enhancing or constraining capabilities and functionings in this contested context.

Comparative experiences of compulsory detention and voluntary admission revealed capabilities distinctions. Lawrence described a benefit of being on Section and in an Intensive Psychiatric Care Unit:

...it's an unusual place psychiatric hospital, you can ... push the boundaries kind of as much as you want, especially if you're sectioned and especially in a place like IPCU...

Lawrence implies that without compulsion, he would have had less freedom to expand social norms of behaviour: a CTO both severely reduced agency, constraining Lawrence to the space of the hospital, and enabled agency within that space. Harry and Monica felt that compulsory admission provided more protections than being voluntary, for Monica in terms of Advance Statements:

...if they section you they'll take your advance statement into account, whereas if they say to you 'if you leave we'll section you', you don't have your advance statement, it's no longer legal in those circumstances ...

Monica highlights a limit of the 'voice, choice and rights' dimension of the Act, and was the only participant to talk about Advance Statements. Hers had four key points: not to have ECT unless everything else has been tried; not to be prescribed chlorpromazine, which '*caused me to gain three stone in weight in five weeks*'; not to be pushed into group therapy; and for her siblings to be informed, even against her expressed wishes. It was signed by her psychiatrist:

R: ...I was quite pleased that he signed it because if you've got a psychiatrist and another psychiatrist tries to overrule it then they might think twice whereas if it's a CPN they might not think.

I: ...does a mental health "professional" have to sign it?

R: Yes they have to sign it to say you're well at the time of making it...

She reveals applications of the bureaucratic and diagnostic power of psychiatrists. And yet Monica vividly described the power of 'voice' which her Advance Statement gave her in offsetting compulsory treatment:

...the last time I was Sectioned I was so upset ... I felt no one was listening to me... there was nothing wrong with me as far as I was concerned. And one of the nurses ... said 'have you got an Advance

Statement?’ and immediately I thought ... I’ve still got a voice. And that was really, really important to me ... in my recovery from that point.

Whilst participants talked positively about being compulsorily detained rather than voluntarily admitted, due to the law providing them with clearer rights, and enabling boundaries to be pushed within a constrained environment, these data actually reveal the limits on human behaviour in open society, and the contingent power of the psychiatric system. Monica unconsciously highlights the assumption of the mental health system that people cannot be treated at home beyond a certain point, reinforcing Lara’s point in Admission Experiences, above, and suggesting the limits of ‘rights’ such as these, for example that they must be considered when under compulsory detention but can be overridden. They demonstrate how, in terms of advance statements, ‘rights, choice and voice’ holders may ultimately only request ‘choices’ that correspond to the preferences of clinicians. In capabilities terms, choice is a cipher for capabilities, from which functionings may be enacted, and voice is a cipher for agency and diversity; a capabilities interpretation shows how narrowly advance statements are shaped, revealing their weakness as a positive social Conversion Factor.

But further, when people are under the aegis of the MHA 2003 their personal Conversion Factors and agency become dominated by social and structural Conversion Factors: state professionals implementing laws. Each person’s capability set is thus inhibited by this legally codified means to reduce risk to the self or others through physical constraint and medical treatment, strongly shaping their functionings. In itself, capabilities may take a passive view of this, as a balance of the state and the individual upholding social justice; the addition of sociology reveals the way in which powers are upheld through these mechanisms, reproducing dominant norms.

Finally, the evidence suggests how the legal dimensions of the psychiatric system benefit formal rights at the expense of substantive freedoms. However, as seen in Admission experiences (section 6.2.1), people can in retrospect agree with the reasons for their detention, suggesting how these formal rights and constraints may expand freedoms in the longer-term, for some, in the last and crucial instance, to uphold life. Constraining freedoms in the short-term may



expand them in the longer-term in this context, raising the same short-term/long-term paradox for capabilities that was seen in the data on suicide.

### **6.3 How processes of diagnosis influence social justice**

The phrase 'diagnosis or label' was used in introducing this topic to participants, in order to allow them the opportunity to follow a social constructivist as opposed to psychiatric model in explaining their experiences. Participants talked about how being diagnosed could help to explain experiences of subjective mental distress, disagreements over diagnoses, and social constructions of diagnosis, and the ways in which these influenced what they were able to do and be in life.

No participants stated that they disagreed with the principle of diagnosis. Participants generally described it in neutral terms, as part of their lived experience. A minority of participants disagreed with certain diagnoses received; some recalled specific experiences that enabled them to place an unwanted diagnosis in a temporal 'box', as a one-off experience.

In sociological terms, diagnosis of mental distress reinforces the dominant understanding that experiences of mental distress are illnesses to be clinically categorised, despite the multiple critiques of the reliability and validity of this, seen earlier. In capabilities terms, diagnosis is a social Conversion Factor administered by clinicians operating within that dominant social norm.

When participants talked about diagnoses they tended to follow lay terminology rather than ICD or DSM terminology. They listed an average of more than two diagnoses, Bridget talking about the most (personality Disorder; paranoid schizophrenia; bipolar and schizophrenia; schizo-affective disorder; postnatal psychosis), several talking about four diagnoses (e.g. Tim: personality disorder, psychosis, bipolar, depression) and only seven participants talking about a single diagnosis. As these were based on memory and non-exhaustive questioning they will be incomplete. People talked about diagnoses of manic depression and bipolar interchangeably.

### 6.3.1 Diagnosis can help to explain experiences of mental distress

Several participants found being diagnosed helpful in explaining their subjective mental distress. For example Fiona found a clear match between her perception and clinicians' diagnosis:

R: ...they said did I know that I was a manic depressive and I went 'no'... and they explained ... it was, you know high mood swings and then you go down low, um, that's how I'd started was after [daughter's] suicide.

I: Right, right, right. And is that diagnosis true? I mean do you, do you...

R: Oh aye (*laughs uproariously*) yes, very much so.

Some participants experienced changing diagnoses over time as accurately reflecting changes in their mental distress. Jon was diagnosed with anxiety-depression from 18 to 26, and then bipolar for the past few years, both of which he saw as reflecting his changing subjective experience. Tim found diagnosis helpful in illuminating unfamiliar feelings, using the language of labels positively:

...it's good now that there's a label put on it, because now I know right this is it, how do I cope with it or how do I cure it? Whereas four or five years ago it was like what's happening, what's going on here?

As later data shows, Tim may be expressing optimism about the accuracy and finality of diagnosis. Jack found his personality disorder diagnosis helpful for thinking about how his life experiences might relate to the diagnosis:

...is it the result of being really unhinged on psychoactive drugs like LSD or ... chemical damage done through drugs, and how much of it is actually a disorder that came to life in me I believe, when my mum and dad split up and also there was violence in the house ... probably it is reasonable for me to believe actually that there is some personality disorder stuff going on... It's not beyond irrelevant.

He also found the diagnosis helpful for understanding the behaviours associated with it and their impact on his social relations:

...it's got a big impact on how I relate to people... it had a lot to do with how I loathed and despised myself with a passion... I got a fright when I

saw [the diagnosis], but ... what's important to me about it is that ... I don't want to be vulnerable to the mood swings and self-harm ... It has been ... much more useful than it was harmful... I had to accommodate this new thing because I understood it to be true... I did a lot of reading about it ... I saw that it fitted, there were some places that it didn't quite fit but hey ho, mostly it ticked the boxes, mostly it helped me understand why I'd been on the mission ... to not feel one single feeling... so it made a lot of sense...

It made subjective sense, even though he did not match it perfectly, and reading around the diagnosis helped Jack to explain some elements in his life and so self-manage his mental distress. As with Arthur, Tim and Fiona with their diagnoses, it enabled him to explain his subjective mental distress, suggesting that diagnoses could offer the potential for self-knowledge, and so expansion of capabilities. However, this required the diagnosis to resonate with subjective experience.

### 6.3.2 Disagreements over diagnosis

Participants found some diagnosis experiences more problematic. On the one hand, Monica accepted depression and psychosis as true to her because they reflected her subjective experience:

I know that I get very, very depressed... and I know that I've psychotic symptoms because I hear voices and sometimes I see things and sometimes I smell things that aren't going on...

However, she disagreed with an additional personality disorder diagnosis, given, as she understood it, because of her self-harm. Her understanding of the wider criteria for the diagnosis was contradicted by her self-knowledge, which was of being sociable and having friends. Similarly, Lara said she '*tend(s) to accept*' diagnoses of rapid cycling bipolar, depression and PTSD, but when at age 19 a psychiatrist diagnosed her with emotionally unstable personality disorder she found this less justifiable:

I don't think that's me at all. I can see why she saw me fitting it then ... I was self-harming and my personal relations with my family were difficult which fit [with the diagnosis], but it wasn't just me that was making my family relations unstable...

She argued that it was her sister and mother's behaviour within the social relations of the family that affected her behaviour at the time, and that a year afterwards these issues had changed. But Lara gained the diagnosis or label from what she argues was a social relational problem because she was already involved in the mental health system, this acting as a prospective magnet for additional diagnosis, individualised in her medical records. This reinforces critiques of the individualisation of diagnosis for what is a socially shaped phenomenon (Tew, 2011, ch.2). Her diagnosis also coincided with a change in Consultant, suggestive of social constructions of diagnoses, further explored below.

Contention over diagnoses could stimulate the use of agency by participants, seen most strongly in those with outsider characteristics. Becky had experienced a psychotic episode after high-dose steroid treatment for a physical illness. There was a tension between her understanding and that of clinicians:

...when I was high and went to see the psychiatrist, they suggested that it wasn't steroids ... because I'd had this period ... before I got ill, of feeling very happy, they said 'maybe that was the start of you getting high... Maybe you have bipolar'. And my sister who's a mental health nurse ... said they shouldn't say that, well it's all about this labelling business. But the psychiatrist said to me 'This is your first psychotic experience. If you have one more, you might get tipped over into being bipolar.' Which was like really alarming... I've just disregarded that. I'm never taking steroids again ... but I don't see why I should have to think 'I'm at high risk of developing some disorder' ... as long as I live healthy and, kind of, follow a good path...

So Becky experienced mental distress, but used her agency, supported by her sister - acting as a contrary social Conversion Factor to her psychiatrist - to '*disregard*' a diagnosis which may have had the implication of keeping her within the psychiatric system. She is also using her agency to do and be things that keep mental distress at bay, based on her own insights.

These data show participants questioning diagnoses that do not resonate with personal experience of mental distress, whilst still not pursuing more fundamental questions about the principles underpinning diagnosis.

### 6.3.3 Social constructions of diagnosis

Where the above data describe how diagnosis did or did not fit with personal experience of mental distress, participants also demonstrated how misdiagnoses happen.

Diagnosis could be dependent on the disclosure of the patient, exemplified in Arthur and Bridget's experiences. Arthur was admitted to psychiatric hospital but was afraid to say that he heard voices. In hospital he was diagnosed with depression and discharged. He then attempted suicide; wanting to end his life as he *'didn't know what was happening'*. His CPN then *'put me with a psychiatrist, I told them I heard voices and all that. Then they put me down as schizophrenic'*. Bridget had a similar diagnostic experience as a girl: *'when I was really, really young they thought I might have a Personality Disorder, they couldn't work me out ... because I wasn't forthcoming about the voices'*. So diagnosis can be contingent on the will of the individual to disclose atypical emotions. This is also contingent on their understanding and trust of psychiatry. This reinforces post-psychiatry's questioning of the reliability and validity of psychiatric diagnoses and call for user experience to be taken more seriously (Bracken et al, 2012).

Bridget had been diagnosed with schizophrenia and bipolar disorder for over twenty years, until recently superseded by schizoaffective disorder:

...when I was really young they thought I might have the personality disorder ... later on I was told I was paranoid schizophrenic and then they said now I've got bipolar and schizophrenia but it's put into one... schizoaffective ... but I don't really care what it is ...I know I hear voices and hallucinate...

She did not perceive that she had changed, but her diagnosis had. This may reflect a change in psychiatric diagnostic practice, codified in the deletion of the diagnosis of paranoid schizophrenia in DSM-5 (May 2013), structural-social Conversion Factors in psychiatry leading to a 'new' diagnosis for an individual, which Bridget has no agency to override, but which she rationalises away using the descriptors that render her experience legible to herself: hearing voices and hallucinating. Re-diagnosis of unchanged symptoms may also result from forthcoming new ICD classifications (planned for 2015). So, diagnoses could

change over time, not only reflecting changes in subjective mental distress, but also changes in structure for psychiatrists working within the medical model.

Caroline presented another experience of how diagnosis could be constructed, influenced by her father's diagnosis:

R: ...for years they said that I had bipolar like my dad... but I'm still to this day waiting on a manic period.

I: So, what explains...?

R: ...I had so many kind of really deep, really dark periods of being so low. And my cousins - all my dad's side - have bipolar disorder. My dad's only ever had two periods of elation ... and my periods of mood swings of going really, really low, mirror his ... But my anxiety is very, very significant and I think that's where psychiatrists ... query if it's elation...

Caroline, who was a trainee psychiatric nurse at the time, disagreed with her clinical team's opinion for six years, only for them to concur with her:

...we just agreed to disagree, they were just like 'well you're a very determined young lady'... I was on Lithium and all sorts of things, but they made no difference. After I'd been on it for over a year they finally accepted that I may be correct and now they have said I do not have [bipolar disorder].

Here diagnosis was shaped by family history, but Caroline also suggests that her father's diagnosis may have been incorrect. So, potentially an incorrect diagnosis was made on the basis of a previous incorrect diagnosis, the piling of error upon error due to a diagnostic process operating on the assumption that past diagnoses must have validity. This also demonstrates the marginalising of patient opinion, even though Caroline was a student psychiatric nurse at the time. In terms of how this misdiagnosis influenced Caroline's experience of social justice, her lack of meaningful participation in her care - an empirical critique of the 'voice, choice and rights dynamic' of the MHA 2003 (Scottish Executive, 2004) - was compounded by her mental distress continuing for several years. During this period her education slowed, it taking her longer to qualify, and so to be able to access productive and valued activities and a comfortable standard of living. If these were the capability deprivation implications for Caroline, what are the capability implications of misdiagnosis for people that

had less authority in advocating for the validity of their own interpretation of their experience of mental distress?

The data suggest that diagnosis only contains elements of social construction, the process being more than trial and error, but less than reliable. This suggests that the post-psychiatry approach of working with peoples' subjective experience and context (Bracken et al, 2012), consistent with the capabilities focus on agency and participation, might be more consistently helpful for people with mental distress than the dominant medical model.

In terms of the meaning of diagnosis for social justice, at best diagnosis was shown to be capable of forming part of a process of regaining a sense of agency over mental distress, so enabling greater potential for expanding capabilities. There was evidence that people can reject diagnoses, challenging the dominant norm, a 'being outside' practice. However, some experienced the frustration of being within the mental health system with a flawed or contested diagnosis. The question of individualised psychiatric diagnoses then being on medical records forever, following what might be a very brief incident in a whole lifetime, raises wider questions of justice and dignity.

The analysis of diagnosis highlights discourses about the power of the state over the citizen, and non-conscious conformity to dominant norms, underexplored in capabilities. The experiences of people with mental distress in terms of diagnosis form a paradigmatic case, revealing weaknesses in the normative assumptions and depth of analysis in the capabilities approach.

## **6.4 How psychiatric medication influences social justice**

Almost all participants recounted both good and bad experiences of psychiatric medication. Only Steve, the most thriving participant, recounted no negative experiences, and only Jack did not talk about psychiatric medication at all. The highest number of medicines named was six (Sophie: Diazepam; Olanzapine; Amisulpiride; Quetiapine; Lamotrigine; Sertraline). Two participants talked about experience of ECT (Bridget and Fiona), and two about depot injections (Arthur and Martin). Participants talked about many different types of antipsychotics, betablockers, antidepressants, mood stabilisers, and tranquilisers. When

participants talked about medication, they commonly used lay terms, and could find it hard to recall detail (e.g. Robert: '*Antidepressants, it was a pink tablet with a big name*'). They also found it hard to recall all their experiences, which commonly spread over many years, and were based on non-exhaustive questioning. Participants talked about the effects of medication and about iatrogenic effects, however the two were often impossible for participants to disentangle. The next two sections distinguish effects and iatrogenic effects for heuristic purposes, but as iatrogenic effects were often discussed by participants as being tangled with effects they emerge throughout, the more explicit examples contained in the second section. In capabilities terms, psychiatric medication, its effects and iatrogenic effects, is a social Conversion Factor with the potential to impact on the capabilities and functionings of participants.

#### **6.4.1 Psychiatric medication has unpredictable impacts on social justice**

Some participants (Arthur, Barbara, Ivy, Jim, Martin, Monica) had been on essentially the same medication for between 10 and 30 years. None suggested that there was an exit strategy from medication for them. Others had been on medication for a decade or more, sometimes prescriptions varying responsively to a major change in their subjective mental distress. Others again had only recent experience of subjective mental distress and had experienced regular changes in medication. Only Robert and Becky were definitely not currently taking any psychiatric medicine.

Psychiatric medication could, in a complex mix with other factors, reduce subjective mental distress, if with sometimes sizeable costs. It could also, in a complex mix with other factors, form part of a base to enable participants to expand their functionings. However, capabilities were sometimes frustrated in the context of long spells on medication; and medication was experienced as unpredictable.

People with surviving characteristics experienced limits to the efficacy of medication in reducing mental distress and improving their health capabilities. After eight years in the statutory mental health system, Lara still did not have an established medication; the right crisis support, psychotherapy and cognitive



practices to improve predisposing and precipitating contexts for mental distress had more consistent impact on managing her mental distress. Harry, Gary and Barbara were prescribed psychiatric medicine for many years without meaningful improvement. Gary:

...the 400 milligram amitriptyline every night for twelve, thirteen years and then suddenly to stop taking it because I'd got to the point where I was still depressed, I never went back to the doctor he would just have upped it another hundred milligrams ... and it wasnae the answer...

Barbara had been prescribed Trazodone since 1993:

I: This might seem a silly question because you've been on it a long time. Does it help you?

R: Not really. If it helped me I wouldn't be sitting greeting and things like that. But they're putting it down to my daughter and me looking after my wee grandson, that's what's the matter with me, and it's not it's my mental health... I ended up doing my wrist, cut all my arm, slashing it, last year.

Barbara suggests that her mental distress is not precipitated by her current relationships but is somehow more integral. But her medication had not meaningfully decreased her subjective distress after twenty years. Similarly Martin, after thirty years on an injection and tablets, noted that medication *'doesn't make much difference'*. Whilst cases like those of Barbara and Martin are impossible to fully evaluate, as their experience cannot compare to life without medication, they can compare what they have been able to do and be with the doings and beings that they aspire to have, and can see themselves coming up short. Martin: *'It's soul-destroying. I'm trying to work, maybe have a career all this sort of thing, but what can I do?'* When Martin's life is looked at objectively, as with Barbara and others, with few of the capabilities that he values able to be achieved, it is understandable that he says this. This is a key insight into how the basic metric of capabilities, understanding what people are actually able to do and to be in the context of a dignified life, can make a distinctive contribution to understanding what is important to people and to wellbeing, beyond what Wallcraft (2011, p.273) calls the 'medicalised disease-specific approach' to measuring quality of life in approaches to evaluation that assume that diagnosis and medication each have reliability. Using capabilities, gaps in doing and being that hold meaning to individuals can be identified, and

the analysis can also contextualise the interaction of medication with the social world.

Reducing subjective mental distress was valued both in itself and for reducing the risk of social harms such as prejudice resulting from the public expression of mental distress. Fortnightly depot medication and other work with doctors had helped Arthur not to speak out loud to voices in his head, so avoiding harassment that he had previously experienced. Bridget attended hospital for a fortnightly dose of maintenance ECT *‘to keep it, to keep you balanced, to save you getting ill and needing to go in and get twelve [doses] you know? ...I find it helps...’* As with Arthur, she continued to hear voices with medication: *‘even to this day the doctors have said that I’m treatment resistant, because I hear voices twenty-four/seven, when I’m well they’re whispers’*. But she had been out of hospital for 17 months, a major change in what she was able to do: *‘between the lithium and the clozapine and ECT it’s keeping me really stable’*. Bridget expected the maintenance ECT to continue indefinitely. Whilst ECT *‘definitely’* negatively affected her memory, for example recalling peoples' names, this was outweighed for her by the reduction in mental distress. Similarly, Fiona’s memory was so badly affected by ECT that she forgot that her daughter had committed suicide, and her son had to explain this to her all over again. But she still viewed the treatment as the right thing as it reduced her depression. ECT thus positively and negatively affected who these two people with surviving characteristics could be: people with reduced memories, but also people with less subjective distress and fewer crisis-driven hospital admissions.

Arthur, Fiona and Bridget demonstrate that positive experiences of medication come in a context: for example, when physical security was threatened, or terrifying hallucinations, regular hospital admissions, or deep depressions are experienced. They tolerate what for other citizens might seem unacceptable inconvenience and side-effects, as these were outweighed by benefits in how they are able to be and therefore what they may be able to do. In capabilities terms these are adaptive preferences, capabilities in life being sharply reduced to basic functionings. In terms of social understandings of mental distress they beg the question of whether sufficient non-medication alternatives - social adjustments - are available, addressed further in chapter seven.

Sophie had a diagnosis of schizophrenia, taking *‘Quetiapine which is an antipsychotic, Lamotrigine which is a mood stabiliser and Sertraline which is an antidepressant. It works so it keeps me going’*. However, context for ‘works’ is necessary: she still heard voices but her positive attitude was placed in context - she had previous medication with intolerable iatrogenic effects (see next subsection). But she felt that the medication had provided her with a base to do things like attending university, and being able to concentrate, read and not experience mental distress that, as she noted in chapter five, placed her dignity at risk.

Lithium had reduced subjective mental distress for Lawrence after he found newer generation bipolar medications ineffective. But he also located this earlier ineffectiveness socially as, similarly to some other participants such as Sophie, he kept stopping medication, hoping that his mental distress would be resolved without it, and continued doing activities he described as detrimental to his health, demonstrating a tension between agency and wellbeing. He, as with others, detailed a trial-and-error approach to psychiatric medicine, requiring faith and tolerance from the ingester:

I don’t know if it’s taken time to adjust the medication or, finding the right medication or the amounts that they’re giving you but I just couldn’t cognitively function the way I wanted to, or just the after-effects of the illness as well... I just felt so ... disabled by the medication ... I wasn’t lucid and I wasn’t ... sharp...

This shows that whilst medication could reduce subjective distress, it could contra-indicate the conversion of capabilities into functionings. However, unlike for Arthur, Fiona and Bridget, it did not lead to adaptive preferences for Lawrence. In contrast, the most effective medication for reducing mental distress for Ivy was Clozapine, which requires regular blood tests,<sup>7</sup> but for Ivy: *‘What I wanted to do that I can’t is be an aid worker in Africa because I have to get my bloods taken every month’*. Her capability set had been narrowed due to the specific medication.

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<sup>7</sup> Clozapine causes agranulocytosis, a condition involving a decrease in the number of white blood cells, meaning that patients require 4-weekly blood tests (<http://en.wikipedia.org/wiki/Clozapine>), sourced 31 March 2015.

Kirsty had tried stopping her anti-depressant but experienced increased subjective distress. For her this begged the question of whether she would ever be able to stop taking it, and the implications of this for the ambiguous concept of 'recovery':

R: I don't want to say that I'm recovered because ... I'm still using the chemical crutch of the medication ... am I really recovered if I'm still relying on that so much? I've got the feeling that I'm using the medication to just hold it back a bit and if I kind of 'let up' for just a second then it will just come back... and overwhelm me. So, I don't ever feel like I'm recovered at all. But ... I can kind of manage it...

I: If you 'let up' do you mean in terms of the medication or in terms of your lifestyle, keeping yourself busy?

R: Yeah, both of those.

Kirsty describes a complex mix of subjective distress and the intended medication effects mutually affecting her confidence in maintaining her functionings, evidencing that there can be a problem distinguishing the impact of medication from being 'truly' recovered: the biomedical model combined with the individualised focus of the recovery model (chapter two) can be seen here to be maintaining Kirsty in a predicament (Barham and Hayward, 1991). In contrast, Lawrence and Steve, with thriving characteristics, did not cite this as a contradiction, suggesting an archetypal difference between the two characteristic groups, with surviving including having a lengthy struggle with medication alongside other aspects of life.

So, psychoactive medication could contribute to reducing mental distress, acting as a social Conversion Factor for enhancing functionings and capabilities. But medication could also be unpredictable in its effects, and there was evidence of long-term prescription of under-effective medication, leading to threats to functionings and capabilities as extreme as suicide attempts. These unpredictable experiences could result in insecure functionings and frustrated capabilities, demonstrating the capabilities limits of medication, necessarily shaped also by the social context, indicative of surviving or thriving characteristics.

### 6.4.2 Iatrogenic effects negatively affect social justice

Iatrogenic effects, or side effects, for psychiatric medication are often known and anticipated by the pharmaceutical industry and mental health professionals, noted on medication information sheets, and based on empirical experience (e.g. short-term memory loss from ECT (Busfield, 2011, pp.172-173), weight gain from antipsychotics (Moncrieff et al, 2009), or sexual dysfunction from SSRI antidepressants ('close to 40% to 50%', Balon, 2002, p.43).

Almost all participants talked about iatrogenic effects, this section describing the most explicit examples. For participants with thriving characteristics, taking medication was an ongoing and manageable balance between efficacy and side effects. For other participants, side effects from some medicines reduced their 'abilities to be and do things that make up a minimally good, flourishing and non-humiliating life for a human being in the contemporary world' (Venkatapuram, 2011, p.20), or their social justice. For example Becky had panic attacks, Monica extreme weight gain from chlorpromazine and Francine weight gain from Lithium, so they stopped taking them. Sophie had to give up a radiotherapy course as drowsiness made her a risk in operating machinery. Jim could not have sex because of side effects combined with medical advice not to use Viagra. ECT led to short-term memory loss for Bridget and Fiona and several participants reported 'zombie-like' side effects of medication in hospital. Iatrogenic effects could disrupt social justice for some.

'New generation' medication could in itself engender mental distress, for example Kirsty was prescribed Prozac, tricyclic antidepressants and Seroxat at different points from age 13, Seroxat making her feel suicidal, an iatrogenic effect that is now formally recognised.<sup>8</sup> Sophie had dismal side effects with two 'new generation' antipsychotics:

I was on Olanzapine, that made me balloon... Then I was put on Amisulpiride, and that ... messed up with my hormones. I actually ended up lactating on [CPN], which was creepy as hell so I decided to stop taking that.

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<sup>8</sup> See [www.sehd.scot.nhs.uk/publications/DC20030610Seroxat.pdf](http://www.sehd.scot.nhs.uk/publications/DC20030610Seroxat.pdf), sourced 31 March 2015.

These experiences reflect the concerns of post- psychiatry about this newer generation of antidepressants (e.g. Tyrer and Kendall, 2009; Bracken et al, 2012).

Jim had taken lithium since 1984. It interfered with his potency, so he took Viagra, but his psychiatrist said this made him aggressive, with which Jim disagreed. Although the hospital had also said that Chlorpromazine had this effect on his libido, Jim said '*the lithium's always been down on me*'. This reveals tensions between side-effects of prescribed medicine and the individual's need for sexual expression; and between the individual's solution to sexual expression and psychiatric opinion of the side-effects of that solution on the individual. As Jim was a Registered Sex Offender there may be wider considerations outwith this data explaining this restriction on Jim's capability set, linked to protecting the capabilities of others to thrive. Jim's position raises the problem that his sense of agency may be harmful to others. The domains thesis, and the capabilities approach more generally, is based on an assumption of rights to capabilities for those that experience social injustice, but Jim's case provides evidence to contribute to discussion within capabilities of how the framework addresses the problem of when securing a domain for one person places the securing of domains by others at risk, addressed somewhat in Nussbaum's critique of Sen's more liberal interpretation of freedom (2003). The analysis of this again demonstrates the benefit of 'standpoints and distance - combining the experientially based knowledge of service users with rigorous analysis' (Tew et al, 2006, p.vi) to interpret situations, and demands further empirical research.

Becky experienced panic attacks as a side-effect of anti-depressants, and was offered beta blockers to counteract them, but this experience led to anxiety about her reactions to other medications:

...because I'd had such an extreme reaction ... I was now so concerned about side-effects of medication. So as soon as they mentioned valium I ... read everything I could ... and basically it said that valium could cause depression, and I was terrified of being depressed after I stopped being high and that I would kill myself.

This reinforces the difficult position in which unpredictability of medication effects and iatrogenic effects places people. These combine in unique ways for each psychiatric medication and each individual.

Iatrogenic effects could disrupt participants' relations with their psychiatrists. Lara had developed abscesses when on Quetiapine, a second generation antipsychotic. The internet suggested that Quetiapine might affect the immune system. She asked her psychiatrist who said there *'can't possibly'* be a link. Her definitiveness made Lara suspicious, so she planned to ask a pharmacist friend: *'I just want to be making an informed choice'*. She wanted to avoid *'making a thing' out of it* as when 18 she made a negative comment about her psychiatrist in a CPA meeting and was *'ditched completely'*. She trusted her current CPN and psychiatrist *'more than I have anyone for a long time but ... in some senses the fact that I trust them more makes it harder'* as she did not want to risk losing them. This shows the power of psychiatry over individual agency and the careful navigation required to question psychiatric judgments. One difficult incident made Lara consider her actions for years ahead; and when a psychiatric team were good the risks of challenging them and receiving rejection were higher than for a 'bad' team. It requires adeptness of agency to challenge dominant discourses of professional knowledge and power. This suggests an added reason why so many participants had mixed medication experiences, but remained compliant. The social-structural Conversion Factors of biomedical norms of treatment combined with psychiatric power and practices can be seen to constrain the agency of patients in this context.

So, the uncertainty of effectiveness of medication combined with iatrogenic effects formed a complex and unpredictable dimension of living with mental distress, revealing lived experiences of the social-structural system of psychiatric norms and powers. The evidence suggests that peoples' ability to 'be' themselves - for example as people of a particular weight, or as sexual people or to have good short-term memory, were compromised, and so their social justice deferred. The power in the psychiatric system was demonstrated in how people struggled to use their sense of agency to 'do' things about iatrogenic effects, such as to confidently discuss this with a psychiatric professional.

### 6.4.3 How biomedical norms of treatment shape how people are able to use agency

The power of biomedical norms of treatment in the psychiatric system was reflected in further tensions emerging for participants around strategies for negotiating medication. The role of agency in this context, revealed distinctions in terms of 'being outside'.

Some participants with only surviving and thriving characteristics in this context spoke about their compliance with medication regimes, for example Bridget (*'I'm a stickler I always take my pills'*). Others would stop, but with psychiatric consent, for example when there was disagreement over diagnosis and so medication, or after very long periods of medication not influencing mental distress.

Other participants also with surviving and thriving characteristics took more subversive approaches to medication. Some stopped of their own volition after experiencing improvements in mental distress, then attempted to live without significant distress and without medication, only to revert back to it, usually with psychiatric intervention. This could be a repeated pattern. Others stopped as improvement was so intangible (e.g. Gary). Others sometimes lied about taking their prescribed amount of medication (e.g. Caroline, Lawrence), using their agency whilst avoiding a potential struggle with their psychiatrist.

Whilst participants with surviving and thriving characteristics in this context followed - implicitly or explicitly - the dominant biomedical norm that psychiatric medication is helpful and probably required for stable mental health, two participants with characteristics of being outside (Jon, Becky) made particular objections to the dominant model of treatment. Jon:

How would I be [If] I'm off the medication? I would like to find out, but the doctors don't want to hear... So it's like, it's a crime to be getting well. That's why I resolved to do my own thing. It's the system, the nature of it all is making me rebellious because you go on medications, have no back-up plan if you're well, to come off them. That looks at ... prevention... [Doctors] don't want to talk about these ... things... They see that I might take not well...



Jon points to the limits of the medical model, with no exit strategy from medication, the social-structural '*making*' him rebellious. Jon argued that the agency of psychiatrists is structured by the ideology of their training, and within pharmaceutical dominance: '*They've been taught in a medical way, and ... these medical companies are making all sorts of money...*' and felt forced into a path of taking medication with no alternative treatment model considered:

I've not got a problem with the Crisis Team, their qualifications or how they go about their job. The only problem I've got is that you'll not get treated if you're trying to bring any other beliefs, or how you want to see your treatment go... So I took up my own plan. I've stopped taking two medications.

This follows Plumb's (2012, p.22) argument that the medical-ethical principle of informed choice only exists if people have alternative choices that they are able to pursue. Jon stopped taking these medications for several months, then wrote to his psychiatrist:

I said 'I'm getting less side effects and I feel better', so they cannae give me a hard time... [W]hen I go to the doctor ... I don't hear what I want to hear - so I end up ... doing my own thing. He can either write down 'this is the sort of thing Jon does, it's in his personality' or he could be more honest and say there might be a reason why I do that.

Jon indicates the problem of disagreeing with the psychiatrist, which faced Caroline and Lara about diagnosis and side effects. He also reveals the inevitability that the psychiatrist shall then clinically judge the individual, as with Lara's experience with 'personality disorder' (diagnosis section 6.3.2), which will then be on the individual's medical record. Jon posits that his psychiatrist might make a clinical judgment of his personality, not of his reasoning, in a context in which his lived experience is that he will be expected to take medication indefinitely. Psychiatric patients are left in a position in which if they use agency to disagree with their psychiatrist this risks being categorised as a potential symptom or re-diagnosis on their medical records, however socially embedded the issue, fleeting the instance, or well-grounded the argument.

In Interview One, Becky said that when feeling depressed she had avoided formal medical services, fearing admission to psychiatric hospital following memories of

her father's psychosis, hospitalisation and subsequent suicide. Instead she saw her university counselling services and had borrowed their Lightbox. She had stopped alcohol and drugs and tried to live a healthy and balanced life as she wanted to be medication-free. At Interview Two she had since seen her GP about '*horrible thoughts*':

I want it to be in my notes just so that people are kind of aware. But I said to her 'look I don't want drugs... I ... don't agree with it...' and she was like '...it's fine I don't want you to go on them either' and she was like 'you have to reduce stress...' and ... 'don't make any rash decisions' and I was like 'oh that's good advice actually'.

The doctor's support made it easier for her to then tell organisations that she had to stop her volunteer work for them. So, Becky was avoiding medication, and managing her distress socially and psychologically. However, she wanted her distress medically recorded as a kind of 'in the last instance' need. She used her GP to circumnavigate medication, and the GP's authority made it easier for her to use her agency to facilitate the social change required. This reinforces the power of the 'medical' but suggests an alternative model to 'medication and diagnosis first': doctors as advocates of social change?

This section has described participants' lived experiences of medication, including iatrogenic effects, in shaping what they were able to do and be. The data revealed how medication could offer a platform for people to be able to do and be different things, potentially expanding their functionings and capabilities, but not without costs; how capabilities could be lost when taking prescribed medication; how medication could be unpredictable, including stimulating feelings of distress and iatrogenic effects impacting on social justice outcomes; and it revealed participants' constrained agency in relation to medication norms, revealing a characteristic of those 'being outside' as expressing a stronger sense of agency, questioning dominant biomedical discourses.

The mixed and distorting impacts of medication and iatrogenic effects produces an unpredictability which problematises the biomedical starting point that medication is a necessary base for supporting people with mental distress. Haphazard experiences of psychiatric medicine, even aside from iatrogenic

effects, are a - usually unstated - norm for people with mental distress (e.g. Balon, 2002; Dowrick, 2009b). The diversity of experiences ultimately begs the question of whether medical treatment would be more accurately described as being medical trial. But unlike social or psychological interventions, psychiatry has the legal power - a dominant social and structural Conversion Factor - to ultimately impose medication.

The complex medication experiences of participants also provide evidence of why people remain faithful to medication. This is partly explained by the materiality of negative subjective mental distress, including suicidal feelings, but also by the norms of social relations with clinicians within the dominant model of diagnosis and medical treatment, and dominant social norms of health and illness. The materiality of mental distress, the shaping of priorities and expectations for responding to and managing the experience, and the context of dominant medical discourses, start to offer an explanatory logic for the social justice patterns experienced by people with mental distress.

## **6.5 Chapter conclusion: how the mental health system influences social justice for people with mental distress**

The chapter findings are reviewed and critically analysed in the discussion chapter, but a few observations are salient at this stage.

The data has shown ways in which the mental system is organised, including through the law, to contain human freedoms and shape subjective mental distress as being a diagnosable and treatable medical condition. Whilst the system could preserve life as the most basic threshold functioning, it struggled to address wider social injustice. When mental distress resulted in people being in contact with the statutory mental health system, experiences of hospital and professionals could be difficult, even frightening. Diagnosis could be experienced as helpful in gaining subjective understanding of mental distress but when not resonant with personal experience it was experienced as distressing. Medication similarly could help people with regaining agency, but was unpredictable, and could be ineffective, even counterproductive, including the impact of iatrogenic effects. The chapter has shown how people both position themselves and

become positioned towards surviving or thriving characteristics, and into being outside.

These elements of the mental health system are, in capabilities terms, social Conversion Factors. The data have shown that these can operate both negatively and positively in relation to enacting functionings and enhancing capabilities, including at the same time, for example medication being perceived as simultaneously beneficial and unhelpful, and hospital concurrently needed and unwanted. So this capabilities concept has been originally applied to contribute to a least reductive explanation of why and how the mental health system can fail to achieve social justice for people with mental distress.

In sociological terms the section has demonstrated how the structures of power which shape social order influence social justice outcomes for people with mental distress through regulation and containment embodied in laws and social practices. It has drawn out that these dynamics are complex, the agentic, social and structural working in tension, the power of psychiatry not removing agency in a highly socially ordered context of hospitalisation, professionals, diagnosis and medication.

How the social justice of people with mental distress is influenced by the mental health system in these multiple ways, as with the feeling of experiencing mental distress in chapter five, constitutes only part of a least reductive understanding of the social justice experiences of participants. The analysis now turns to wider social justice experiences outside the mental health system.

## **7 Living in society with experience of mental distress**

### **7.1 Introduction**

This chapter explores examples of how broader social relations were experienced and perceived by participants. In the interviews, participants talked about whom they spent their past and present time with, and how this time was spent. This data was not necessarily linked to their mental distress experience, demonstrating that this does not always hold a defining role in the lives of people with experience of the mental health system. The chapter first draws out data in which participants explained how they used their agency to manage subjective mental distress for themselves, including structuring their time and involvement in different types of group. It goes on to examine how intimate and family relationships, and discrimination and prejudice interacted with experience of mental distress and contributed to the social justice experiences of participants. Family and intimate relations were prominent in the data; discrimination and prejudice, or the broader rubric of stigma, were not talked about at great length in these interviews framed around social justice, in itself of interest due to their salience in the literature. The chapter finishes with an analysis of how the experience of mental distress interacted with education, work, and income, socially valued domains of life in which the macro level data (chapter two) suggested that people with mental distress tend to experience social injustice.

### **7.2 Managing mental distress outside the mental health system**

Every participant talked in the interviews about doing ordinary things in life. Gary, Bridget and Barbara cared for their grandchildren, Andy, Robert and Steve watched football, Jim went bowling and dancing. Tim, Ivy, Jim, Francine and Fiona went to church. Fiona was looking forward to a week's holiday in Iona with her church group, who acted as social Conversion Factors, accepting her with mental distress and without prejudice, enabling this capability to be converted into a functioning. Some participants had a passion for film, TV, listening to music or reading. Several spent time at university or college (Kirsty, Francine,

Sophie, Becky, Jon) or at work (Steve, Lawrence). Two participants spent a lot of time on computers (Harry and Martin). The 'mundanity' of these doings is important to note. People with mental distress are not living in distress all the time and each has a unique set of interests as with every human, the capabilities concept of diversity acknowledging this (Davidson et al, 2009). These data indicate that mental distress does not always hold 'master status', and reveal individuals' sense of agency in areas of life that would not be seen if the analysis was restricted to service usage (Beresford and Wallcraft, 1997, pp.75-76). These data also indicate ways in which it is functionings, what is actually done, rather than capabilities, what they could otherwise do, that ultimately matter to the sample.

However, only Steve and Lawrence, both with thriving characteristics, pursued no specific activities in relation to managing subjective mental distress, although even for them some of their choices were still influenced by their past experience of mental distress. Lawrence identified how developing a number of meaningful activities together, such as upholding his job, moving in with his girlfriend and monitoring his improvements in playing tennis helped him to appreciate how he was thriving 'outside' mental distress:

...it's kind of little milestones ... when you look back it's like maybe in last year, year and a half, two years ... when I've got back to what I would say being completely well on a day-to-day basis and being where I want to be and my illness not impeding me on a day-to-day level, or the history of my illness not affecting where I am...

If subjective distress is not simply resolved through the medical model of statutory mental health services, diagnosis and medication, how do people then use their agency to manage their mental distress outside this? Participants demonstrated how they used agency to manage their mental distress in three areas of civil life: doing different things; using routine and structure; and using voluntary sector mental health groups and activities as opposed to mainstream groups and activities. The analysis helps to explain how capabilities could become functionings in these contexts and the ways in which personal and social Conversion Factors work together to influence agency and the patterning of social justice.

### 7.2.1 Using agency to do different things

Most participants said that they did things that specifically aimed to manage their subjective mental distress. Some did exercise or walking (e.g. Jon, Lara, Harry, Monica). Gary found cooking therapeutic. Jack specified a mix of activities that helped him manage his mental distress: *'Cycling, playing music, writing, reading... I'm ... very interested in feeding my spirit, health and healing and recovery are ... the biggest part of why I'm still alive'*. So, people could use their agency to pursue specific functionings and manage their mental distress.

Several participants demonstrated the use of agency to calibrate their functionings in attempts to reduce subjective distress. Since her psychotic 'high' Becky had given up drinking alcohol and her occasional use of recreational drugs, as she was now *'scared of being put in a psychiatric unit. And losing all control... I'm probably also scared of, like, suicide... And I'm scared of psychosis'*. Jon focused on the agency required to change functionings in his life:

You need to put in a lot of hard work yourself... [Since] I gave up caffeine, coffee ... I've had less problems mentally... I think the coffee and anxiety and the stress and distress of it all, the tablets all going together, it was driving me mad...

Sophie described how she had:

...cut back on social things ... it was like 'no wonder I was unwell' because I was working, I was volunteering at three different places, I was in a band... I knew things were bad so I was just trying to fill up my life with activity.

Whilst frustrating, *'I've kind of got used to it now. Like my friends are ok if I ... have to cancel at the last minute...'* She highlights how converting too many capabilities into functionings can affect her mental distress, and the assertive agency required to manage this, whilst highlighting the positive social Conversion Factor of the role of friends, enabling the functioning change. This corresponds with the evidence on the unpleasantness of subjective distress and also the way in which the psychiatric system constrained functionings as part of treatment, the difference here being agency and diversity - people choosing where to limit their activities.

Doing different things could lead to reflection on how life was before mental distress. Monica noted that although her life was still *'quite rich'*, lower income meant that she was unable to go to the cinema and theatre when she wanted, and she missed the professional friends that she used to have. Social and personal Conversion Factors had operated together to reduce her capability set and social justice. For Harry, since his mental distress, watching rugby, mountain climbing and holidays *'don't happen'* but he argued that he could thrive without these as he had created enough *'distractions'* and *'variety'* to fill time within the home to which his mental distress confined him: computer-based activities, watching DVDs, and gardening. There was much less poignancy than Monica's expression of a lost past - capabilities changed, compared to capabilities lost. In this context Harry shows characteristics of *'being outside'*, contentedly pursuing a life of personally valued, rather than socially valued (Hopper, 2007, p.874) activities; Monica with surviving characteristics, seeking a socially valued life. These examples reinforce the value in a capabilities understanding of social justice of people both holding a wide capability set and also of having the agency to convert these into functionings.

However, the outside world impinges through its normative structures and expectations about how individuals' sense of agency should be used, and so for Harry mental health professionals - acting as social Conversion Factors - worked with him, aiming to change his agency to achieve the dominant norm of going outside: *'I usually see somebody once a week who comes and spends an hour or so with me and will try and force me to go out [laughs]'*. Harry accepts that his subjective distress confines him largely to his home, but he is content with this personally valued activity. Nussbaum and Sen can be combined here. He is not at great risk of breaching Nussbaum's threshold capabilities - he views himself as having a rich lifestyle, engaging with the world through the internet - albeit a very different one from his pre-distress 'great outdoors' lifestyle. So, he is taking an autonomous approach to managing his mental distress, expressing Sen's diversity principle. Further, the role of mental health workers is to bring Harry back into socially valued behaviours of leaving the house, but this is shaped by the dominant social norm of what is understood as a valuable lifestyle. The mental health professionals are following the dominant medical model of trying to make Harry 'normal', rather than following Plumb and Beresford's concerns for



the need to respect atypical behaviours (chapter two), the work of these authors demonstrating compatibility with capabilities through Harry's story.

Caroline demonstrated changes that can exist over time between activities that focus on managing mental distress and more autonomous activities. What she did each day at the time of Interview One was strongly shaped by her subjective distress:

...until recently my week was structured between appointments, the dog ... a course that I was doing on mindfulness, and cleaning (laughs), unnecessarily. And generally just ensuring that I could keep myself motivated. And so, yeah, that generally would keep me for a full day...

At Interview Two Caroline said that at Interview One she had been '*really medicated ... stuck ... unwell*', and now '*I feel a lot more sane, I'm off a lot of medication, I have a lot more independence... I have reduced appointments...*' She had also passed her driving test:

...that's the first thing I've ever ... achieved without having external support or ... a note from the doctor to say 'oh you know she's a bit skew-whiff at times you know go easy on her' ... it's just driving a car but ... it's the start of hopefully many more things that I'll be able to start doing on my own.

She had '*came on more in the last six months than I have in the last six years ... it's a great feeling, scary though ... believe it or not I am probably the most well and 'stable' ... person within my family ... and I have no idea what to expect*'. Caroline had put her applications for volunteer work related to her profession as a psychiatric nurse on hold so she could take care of '*loose ends*' in terms of her mental distress, so when she does volunteer she can do it '*to a fuller degree*'. She was now involved in a woodwork project, getting away from the psychological, '*thinking and talking*'. She ultimately wanted to get back into psychiatric nursing and had renewed her nursing registration. Was she getting by or thriving? '*About half way ... I am not just existing at the minute but I am not yet in full blossom, however I can see that it's a possibility of thriving now*'. 'In full blossom' being a metaphorical rendering of enacting a wide capability set.

Caroline expresses both how powerfully her subjective distress had dominated her functionings and sense of agency, and some of the issues in changing her

capability set 'beyond' her mental distress. First, isolation and uncertainty. Second, navigating the judgment of family in terms of changing role and identity. Third, the careful navigation of functionings. Fourth, learning to drive is potentially a 'fertile functioning' (Wolff and deShalit, 2007) which has potential for widening capabilities. But navigating her journey back to working in her profession - a capability still unavailable - required her to use agency to change her functionings from applying for directly-related volunteering to a woodwork group, which helped to reduce her mental distress. So her subjective mental distress continued to influence her choices of functioning, the structuring of employment suppressing her capability of regaining her previous functioning of psychiatric nursing. Caroline was aiming to achieve a more secure capability set in the future by using her agency to focus her short-term functioning choices elsewhere. This demonstrates the need for a capabilities analysis over time, a gap noted by Riddle (2010). It also reinforces the finding that when experiencing strong subjective distress what can matter is finding the right personal functionings which are likely to ameliorate distressing feelings for the individual. It further reinforces that, as subjective distress reduces, what matters for social justice is having the agency to be able to access alternative functionings from a wide capability set.

As with medical model interventions, using agency to manage subjective mental distress also did not guarantee a complete resolution. Francine expressed the frustration of 'doing the right thing' but not getting the right outcome:

I don't drink, I don't smoke, I don't take recreational drugs, I do a little bit of exercise... I eat half-decent food, I've got my own place that I try and look after, I'm trying to keep my life going by going to university and doing something productive... and then being in [deprived area] (starts crying) you're surrounded by some of the poorest souls in Glasgow and I sit in the Community Mental Health bit and you see some of the people coming in and ... they've drank most of their life, they stink of fags and you just think, it's not fair...

Yet the social determinants of mental distress do not absolve those less likely to experience it from doing so. As UK commentator Stephen Fry, writing after a

suicide attempt noted: *'I don't have the right not to have those feelings. Feelings are not something to which one does or does not have rights'*.<sup>9</sup>

The data in this sub-section can also be interpreted in terms of adaptive preferences. The data to a degree reinforce Sen's notion (see Section 3.2.5) of people being 'too subdued or broken' (1992, p.149), in this context through the impact of subjective distress, to make socially valued choices, so adapting preferences. But this is not the end of the story once empirical examples are looked at, and the data reveals the binary underpinnings of Sen's notion of adaptive preferences. Sen's interpretation is that people have an effective choice or they don't, they are 'broken' or not. Harry's experience for example demonstrates how Sen underplays the complexity of the relationship between agency and what he calls 'social discipline' (1992, p.149), and Caroline demonstrates the temporal character of adaptation. The examples persistently highlight the relational character of adaptive preferences in real-world situations, with many elements influencing what people do and be. This indicates a limit to Sen's interpretation, so suggesting that more theoretical and empirical work using capabilities is required to clarify and demonstrate the empirical and theoretical usefulness of the concept.

So, participants used agency to manage functionings in the context of both mental distress and dominant norms, demonstrating the materiality of mental distress and the complexity of enhancing freedoms and achieving social justice. This also suggests that defining subjective mental distress as the disruption of agency (Tew, 2011) is not a sufficient definition; agency may be disrupted, but remains in particular ways.

### 7.2.2 Developing a routine or structure of activities

Using agency to develop a structure or routine of activities was also significant to participants in managing their subjective mental distress. Some used agency to actively choose their structure and some, such as Martin, had this more strongly structured for them.

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<sup>9</sup> At <http://www.stephenfry.uk/2013/06/24/only-the-lonely/>, sourced 31 March 2015.

Lara highlighted the helpfulness of structure to stave off suicidal and self-harming thoughts:

The first thing is trying to keep my routine ... seeing people ... that's really important ... if I isolate in the flat it makes things worse. But ... there's also ... putting distractions in place so ... I'm never sitting just doing nothing, books and my music and all sorts of things.

But this could lead to problems when Lara was not able to maintain the routine for other reasons: *'for example I have a chest infection and I can't get out to do my normal routine sometimes that'll lower my mood...'* So structure and routine required a sense of agency to implement, which could also be disrupted for other reasons.

The ability to structure activities could also be influenced by mental distress or iatrogenic effects, as for example for Bridget:

Well I've got quite a well-structured life. I try and get up roughly quarter past nine ... and sadly to some people I'm addicted to Jeremy Kyle ... and I watch Judge Judy so ... in between all the adverts I get my housework done. And then ... the dog always needs to get took out ... and then I feed the rabbits and, quite a busy wee schedule. But I'm always tired, I'm on clozapine and lithium, a number of drugs...

For Francine the effects of mental distress or medication made her sleep a lot and tire quickly, also influencing how much she was able to do with her time:

...half my time seems to be taken up by sleeping. The other half is getting myself ready for and going to university, being at university, doing preparation work for university, or writing essays for university... I do socialise a bit but I can become quite tired quite quickly.

At Interview Two she emphasised the way in which agency to use time was structured by her subjective mental distress in another way, not feeling tired but feeling low: *'I'm not really choosing to stay in the house, I'm in the house because I can't face doing anything else'*. A tension could exist for participants with surviving characteristics in particular between maintaining a routine or structure in order to minimise distress, and the way in which mental distress and iatrogenic effects could shape what routine or structure was possible, reducing individuals' sense of agency.

The way in which voluntary sector professionals acted as social Conversion Factors to expand or control routines was seen in the experiences of Lara and Martin. What Lara was able to do and be was influenced by voluntary sector professionals in a women's support organisation (WSO). She outlined at Interview One:

I've got a [WSO] worker ... she'd come to my house one week and then we'd have an 'emotional' in town the other week but her hours got cut down so the last couple of months it's just been ... emotional support every fortnight.

An 'emotional' would involve working on issues of past abuse. The WSO had provided specialised support for Lara as an inpatient, in supported accommodation, to living in her own flat, with finding social circles, and working on the predisposing and precipitating factors that influenced her self-harm. So, they had supported Lara with expanding her capability set, supporting her to live, to develop stronger social relations, and to improve her self-understanding. So Lara's negative personal Conversion Factor of self-harm was balanced by the positive social Conversion Factor of the WSO. However, the insecure funding of the WSO had reduced support for Lara. Thus the structural Conversion Factor of funding for a voluntary organisation had a potential negative impact on Lara's wellbeing which may reduce her capability set, but this is as yet non-determined.

Martin had carers from a voluntary organisation visiting him at home seven mornings a week for the five years since he was last discharged from hospital. They *'Have a tidy up, sit and talk, do social things, see I'm alright, make sure I take my pills and that sort of thing'*. He found the talking useful but he also found the visits something of an imposition, it *'disrupts'* the day and he felt *'relieved'* when they have left. *'First thing in the morning... including Saturdays and Sundays, that's going a bit far (laughs)!' He understood that they were 'trying to make sure that I take my medication, that I'm alright, that I'm kept active, I'm not on my own, that I go out'.*

In terms of what he is actually able to be and do, the workers may help Martin to avoid hospital, supporting wider functionings than he would experience as an in-patient, but at considerable ongoing disruption to his freedom to live his

private life as he wishes. However, Martin does not say that he wishes the daily visits would stop; he suggests that they are too intensive, his agency being overdetermined by the social Conversion Factor of the support workers. However, Martin would like to be being and doing something different, namely working: *'If it's a decent job that pays well I'll be very happy, very happy. It's a start'*. The support workers had referred him to a drama therapy group. Work as he defined it was not treated as attainable - indeed this had been the case for almost all his adult life, and yet he still felt that a decent job that pays well might happen. As with Arthur, another with surviving characteristics, the structural Conversion Factor of how employment is shaped had created a barrier, limiting his capability set. However, Martin had avoided the substantive unfreedom of hospital admission for five years. So there is an ambiguity between whether the work of the professionals was contributing to his wellbeing and agency and maintaining his threshold capabilities, a semblance of social justice, providing him with a base similarly to Lara, or whether Martin was in a 'trap' (Estroff, 1981), and deprived of the 'dignity of risk' (Hopper, 2007). Did supported employment, home activities, rounds of adult education and occasional changes in psychiatric treatment and hospital admissions represent Martin's capability set at its fullest? This example demonstrates the constraints of considering functionings without regard to capabilities in evaluating social justice. Bringing in capabilities in this instance allows us to see the alternative choices unrealised, providing a context for the functionings that are enacted, which utilitarian or resource-based analyses do not allow to be seen. A capabilities analysis of social justice demonstrates the difference here between 'existing' and flourishing, because the acknowledgement of capabilities provides a context for evaluating the functioning.

This data highlights the particular importance to participants with surviving characteristics of developing a structure of activities in order to minimise subjective mental distress, so suggesting that managing distress was a fertile functioning (Wolff and deShalit, 2007), returned to in chapter eight. Sometimes mental distress or iatrogenic effects could constrain participants' agency to create routine or structure. Sometimes agency was strongly contextualised by the normative values of mental health professionals, following dominant medical norms and wider dominant social normativity, and so contradicting the

capabilities principle of diversity, and reinforcing Foucault's social order critique of modernity.

### **7.2.3 Mainstream activities versus mental health-specific organisations: their influences on social justice**

One set of participants tended to have lived most of their pre-mental distress life pursuing mainstream activities and had maintained that, having little or no involvement in specialist mental health organisations and groups (Becky, Francine, Jim, Kirsty, Lawrence, Sophie, Steve). A second group had lived for some years with mental distress and specialist mental health organisations and groups were a significant part of their lives (Arthur, Barbara, Fiona, Ivy, Jon, Lara, Martin, Monica, Tim). The former group almost all had higher levels of formal education than the latter, Jim and Monica excepted. How did these different paths operate as Conversion Factors influencing social justice?

Most participants not involved in mental health voluntary organisations were pursuing mainstream higher education (Becky, Francine, Kirsty, Sophie) or mainstream employment (Lawrence and Steve). They used reasonable adjustments to help them pursue these activities, for example Disability Services at university or flexibility from employers, such as Steve being offered a staggered return to work. This group would use professional, individual mental health services such as psychotherapy, CPNs and psychiatrists, but not service user groups. Thus this group with a structural Conversion Factor of high-level education were enabled to live in the mainstream and pursue socially valued functionings through a mixture of social and medical interventions acting as Conversion Factors, not including participation in peer support activities.

Experiences of participants that used mental health organisations formed a larger corpus of data. Some had used these types of organisation for years (e.g. Barbara, twenty years at a mental health centre; Martin seven years at a Clubhouse). Some had high current usage (e.g. Lara at a Clubhouse '*most days*'; Ivy and Tim going to voluntary mental health organisations four days a week). Organisations provided advocacy support (e.g. help with benefits), creative and therapeutic support (e.g. writing, drama, art, music), and could help develop skills (e.g. bicycle repair). Mental health organisations were places that people

could *'have a laugh'* (Lara), gain *'freedom'* as a better alternative to work and meet *'the same type of people'* in terms of age (Gary), organise holidays (Martin), provide a *'haven'* (Monica), meet people from different walks of life (Barbara), and contribute *'I have skills that can be used to meet the needs of the clubhouse and to help other members ... I feel like I'm needed'* (Lara about clubhouse - *'doing good to others'* being one of Wolff and DeShalit's (2007, p.58) additional suggested domains). However, in section 7.4, later, Arthur suggests that there was rarely a deeper sense of friendship at mental health groups. None of the sample discussed *'independent survivor-controlled organisations'* (Beresford et al, 2010, p.21), distinctively conceptualised in the survivor-influenced literature.

As with specialist education (section 7.6.2), groups tailored for people with mental distress could be valued in specific ways. Monica found a mental health sector art class better for concentration than a three hour open class; Jon had taken up art therapy initially to manage his mental distress (*'We did some drawings and that, they were good at ... putting the confidence back in you'*), and in the process had discovered a new capability, and now occasionally sold a painting. So groups attended with the functioning of managing subjective distress could act as positive social Conversion Factors, offering potential for new capabilities and enabling people to enact new functionings.

Voluntary sector groups could also enable self-understanding, in turn enabling the potential for capability sets to widen. Barbara and Tim attended a drama therapeutic group. Barbara was able for the first time to speak about abuse at school: *'For 50 years I couldn't talk about it. And they done [acted] the nun, do you know what I mean? It was quite good, getting it out'*. She found the social aspect beneficial: *'I've gained a voice ... I've got a lot of my confidence back... But most of all I wasn't alone'*. However, when performances finished it affected her mental distress: *'when that's finished you're back down low again'*. Tim specified how drama therapy enabled a cognitive base from which he could potentially expand his capabilities:

...just say I'm ... feeling so low that ... I can't go into [supermarket] ... the group acts out that scene, and someone plays you, or you could play yourself ... and I could say to myself *'well maybe I could have did this...'* [I]t's just so helpful...



Because of reliance on charitable funding the theatre group was now only meeting monthly rather than weekly, reducing Tim and Barbara's ability to pursue this functioning. This reinforces how vulnerable voluntary sector activities can be to funding changes, as with Lara's voluntary sector therapy (section 7.2.2). Whilst specialist organisations could enable the development of capabilities and so increase the possibility of social justice, these services were vulnerable to funding change, reducing their opportunity to become strong enough positive social Conversion Factors to help people to transition from surviving to thriving characteristics.

Bridget, with archetypal surviving characteristics might have been expected to be a mental health group attender, but was not, revealing non-determinism:

When I was younger they sent me to [name of group] ... I felt like hanging myself it was too depressing ... you'd kind of have tea and socialise and you were all like 'oh I'm this depressed' ... so I says that's not for me ... and they sent me to another place ... I says to myself 'if that's what I'm reduced to I'm going over a bridge' and then they sent me to another place - they were forcing me, nagging at me to go ... I mean I don't really associate with people with mental health problems...

She suggests that two groups not only made her feel worse, but made her feel like killing herself, threatening her functioning of life. Second, '*if that's what I'm reduced to*' suggests she is distancing herself from others with mental distress, as does Caroline in section 7.5.2, distinguishing herself from people that were 'severe'. Third, '*they sent me*', '*they were forcing me*' reveals a normative assumption by professionals that these types of group would be beneficial. Finally, '*I don't really associate with people with mental health problems*' demonstrates Bridget's use of agency to exit from specialist groups, which has led to distinctive social relations from others with surviving characteristics. This highlights the importance of taking account of agency, explaining non-determined outcomes.

The evidence suggests that the mental health organisations can contribute to threshold capabilities being supported, comparable to the mental health system saving lives, and to the role of specialist education (section 7.6.2 below). However, they were vulnerable to funding changes and struggled to act as positive-enough social Conversion Factors to facilitate mainstream capability

sets for people with surviving characteristics. This suggests that being drawn in to mental health voluntary organisations may constrain social justice. Those who remained connected to the mainstream correlated with stronger thriving characteristics, including a generally higher level of education.

### 7.3 The complexity of family relations

Eleven participants lived alone, five with partners, two with partners and children, one with other relatives, two had flatshares and one lived in supported accommodation. Four of those living on their own had partners or children stay with them at times during the week.

Participants talked about the complexity of family relations, including in the context of 'recovery'. Participants described family members acting as positive social Conversion Factors in response to their mental distress, for example providing advocacy for better mental health care and treatment (Kirsty, Becky, Francine, Bridget, Gary), for housing (Arthur) or towards employers (Lawrence). Family members had saved lives (e.g. Bridget), and had helped get participants into hospital when their mental distress risked life (e.g. Harry). Bridget's daughter stayed with her fortnightly to enable Bridget to receive maintenance ECT by consent and return home after general anaesthetic. Families could provide respite (e.g. Becky, stressed by living in the city could get a break with her parents) and could provide a place for participants without much money to have holidays (e.g. Bridget, Martin, Tim).

Others talked about using agency to rebuild relationships with families after experiences of mental distress. Gary's daughter was sixteen and oldest son nineteen at the time his major distress event happened. As part of rebuilding relationships he played pool in the pub every week with his sons: *'...that was just a thing we started doing after I came out of hospital ... meeting up once a week and daein something'*. Sophie described lying to her mother about being in hospital with mental distress (*'I think I said 'yeah, yeah you don't care because you're evil and want to kill me''*), but had rebuilt the relationship.

Steve, archetypally thriving, described how his recovery from mental distress had improved his sense of agency. However:

The experience allowed me to refocus priorities in a huge way... and it's not easy for the people around you... [M]y wife and son, they ... have to show a lot of resilience and understanding ... you can't necessarily expect everybody else to change and move on at your pace or in the same direction ... I'm quite forthright with my wife in terms of giving my opinion ... I'm - it's probably not the person she married... albeit you can say, 'well I've moved on, I've changed, I'm a better person' ... that change can cause ripples for a lot of other people...

Steve had changed as a result of his distress experience, but he articulated the problems that can arise from this, understated in the recovery literature (Cowan and Guise, 2011, pp.36-37) in terms of his family having also to adapt. This mirrors Caroline's experience (section 7.2.1) that she had become the most '*stable*' person in her family, and that therefore she could not rely on them for support. These examples show how 'recovery' is social relational and suggest how converting new capabilities into new functionings can disrupt relationships, indicative of a capabilities explanation of why and how recovery may be hard for some to achieve. These examples also reinforce the relational character of adaptive preferences as seen in Section 7.2.1, here the 'adaptations' of people with mental distress challenging their families to adapt in turn.

So although families could provide a supportive social context for participants, sometimes preserving life or advocating for better support for their relative's mental distress, more complexities were involved. As seen in chapter five, family relations could also be a determinant of mental distress. Whilst it might be assumed that supportive family relations would be indicative of thriving characteristics, and less supportive relations indicative of surviving characteristics, the supportiveness of families of people who remain surviving suggests that families tend to be contributory or contextual, rather than decisive, in social justice outcomes for people with mental distress.

## **7.4 The capability paradoxes of intimate relations**

Participants talked about intimate relations in three ways in the first interviews. First, partners as precipitants for mental distress; second, partners being supportive with managing mental distress; third, partners with mental distress enabling participants to demonstrate a mutually caring role.

Several participants commented on ex-partners, mostly noting their association with the precipitation of subjective mental distress as seen in chapter five. So, partners sometimes acted as negative social Conversion Factors for mental distress.

In contrast, participants talked about current partners in ways which demonstrated their role as positive social Conversion Factors, helping with management of mental distress. Only Steve offered caution in relation to his current partner, in terms of how his recovery affected them, as above.

A year ago Arthur had married his girlfriend of four years. They met at a Clubhouse and had sixty people at their wedding:

...that changed my life so I keep myself well for her Richard, I don't want to end up in hospital because ... she's the kind of woman that would panic... I don't drink, I don't take drugs, so what's in my mind is in my mind due to the voices and illness.....

His relationship was both a motivation to maintain mental health, and to change his lifestyle, avoiding taking substances that tended to confuse his cognition of his subjective distress. Arthur specified another benefit of having a partner:

It's alright meeting other people in [Clubhouse] but they're not actually friends... it is forcing you to meet other people but you wouldn't ... go for a meal or ... a drink... so I was a bit lonely before I met [wife].

His intimate personal relationship overcame loneliness which mental health voluntary sector-based relationships left in place, therefore providing a broader basis for wellbeing, reinforcing secondary evidence associating close confiding relationships with reduced subjective distress (Rogers and Pilgrim, 2003, pp.130-131).

Arthur's wife had a diagnosis of bipolar, as did Harry's wife. Harry used to care for her, and after his breakdown at work, the caring became mutual. Harry felt that his mental distress could be hard for her to cope with '*...especially if I've got to the state where I'm just hiding under the duvet*'. She continued to monitor his medication and his wife still had periods of subjective distress too. Having a partner with subjective distress could enable the expression of caring capabilities by people with mental distress.

Mutual experiences of mental distress could also assist in the forming of supportive intimate relationships. Sophie's partner's grandmother had experienced mental distress:

...and he was raised by his gran so he's cool with it... [H]e's really supportive... [W]e were moving house and I was very stressed ... and had a bit of psychosis flare up and he was fine with it 'just ok, you sit down I'll get it'. Nice of him.

For Lawrence, achieving an intimate relationship was an indicator of his degree of thriving. He contrasted his current position to a few years ago when he experienced several hospitalisations, was living with his parents and could not conceive of having a relationship: *'to be in a great relationship, to be living independently... I probably think it means I appreciate it more than I would have done if I hadn't been ill'*. This shows that he had not adapted his preferences and had converted what was an unfulfilled capability into a functioning, reinforcing the evidence in this chapter of the affirmatory benefit of enacting the functioning, the material conversion of the capability demonstrating what the capability can only offer in theory. He had been with his partner two years and disclosed his mental distress early on:

...and she had no issues with it ... [A] lot of people have varying degrees of mental health experience ... she's had some depression ... when I told her it made it a lot easier for her to tell me ... I think because I'd been open with her, she was able to maybe feel more open with me about a lot of other issues ... not necessarily health related.

These examples highlight beneficial aspects of having a partner who has had personal or familial experience of mental distress and they suggest benefits to disclosure, leading to the potential for a mutually supportive relationship. They show that people with mental distress can act as positive social Conversion Factors for other people with mental distress.

For those without intimate relationships, some did not want relationships (e.g. Bridget) and some did, for example Martin: *'I still want to get married, I still want to make a career, I still want to have children, lead a normal life, oh yeah. That's what everybody does isn't it?'* Jon specified two reasons why it could be hard to find and sustain relationships whilst experiencing mental distress, first the materiality of distress:

90% of the time you're ... living life to deal with your illness... It affects how you communicate in relationships, aye. It affects your ability in making relationships. Because you're dealing with a problem all the time, so you're always... disconnected, in a way.

Second, the structuring of life with mental distress limited his range of social contacts:

I've done all that relationships - single parents and taking on other peoples' problems ... if you've got a mental health issue and you're unemployed you seem to be meeting people in the same scenarios... If you're working your friends are working, so it's hard to break out of the social situation.

So, intimate relationships were structured, with evidence that they could both precipitate and sustain mental distress, acting as negative social Conversion Factors. Yet they could also act as positive social Conversion Factors, helping to overcome loneliness and gain support with mental distress, the data suggesting that people with mental distress could be good carers. The benefits of intimate relationships could only be demonstrated by becoming a functioning; the capability was not sufficient. Disclosure seemed to be helpful in terms of partners being able to emotionally share from the outset, but as for Steve above, the consequences of experiencing mental distress and changing in the process in an established relationship could pose challenges. Where people with mental distress were not in intimate relationships sometimes this was a normative choice frustrated, or a capability deprivation. So, intimate relationships had a strong influence over who people could be, sometimes acting as negative social Conversion Factors, sometimes positively enabling people to do and be more in life, contributing to social justice.

## **7.5 The mixed impacts of discrimination and prejudice on social relations**

Experiences of prejudice and discrimination were overlayed by a perception amongst participants that stigma existed in society independently of their personal experience of it. Bridget: *'a lot of folk are quite prejudiced even to this day... They automatically think 'oh psychiatric you know, you're crazy, you're violent''*. Lawrence: *'obviously there's a stigma attached to mental*

*health...*' The language used ('*obviously*' '*automatically*') suggests that there is no alternative interpretation of social attitudes.

The terms discrimination and prejudice, rather than stigma, are used for the purposes of this analysis following survivor-influenced critiques by Thornicroft et al (2007), and by Chamberlin (2006) whom, amongst multiple critiques, argued that 'stigma' removes subject and object. Prejudice is here defined as detrimental actions or words by people without social or economic power, who may be strangers or people that may be personally valued such as friends. Discrimination is detrimental actions and words from organisations and individuals that hold the power to deny socially valued activities. Discrimination and prejudice are conceptualised as social Conversion Factors, shaped by dominant social norms, with discrimination having a more powerful negative structural influence on what people with mental distress are objectively able to be and do, and on their experience of social justice, but prejudice holding a negative influence on daily subjective life for people with experience of mental distress. The implications of prejudice and discrimination for social justice are clear.

### 7.5.1 Prejudice

Several participants encountered very good attitudes from personally valued groups and friends towards their mental distress (e.g. Lawrence: '*it's not affected my relationships with really any of my friends*'). Steve disclosed to his neighbours and work colleagues and had not experienced any prejudice at all, and Fiona's religious group '*accept me as I am*'. But friends could respond in mixed ways to people when in psychiatric hospital, impacting on relationships. Lara lost some friends when in hospital, as did Caroline:

...when I went into hospital for the longer period of time people just didn't know how to react... I'm now working on getting back into a social life with people that I'm more likeminded with now.

The data suggests that friends can be both supportive and rejecting in response to mental distress, contradicting assumptions of prejudice.

There was some evidence of prejudice by strangers, participants relating specific experiences. Arthur described how people in the street responded to his expression of subjective distress by giving him a look '*I felt rotten at the time Richard ... like I was ... one of these leopards (sic. leper) from away back...*' and how he adapted his conduct in turn, a form of adaptive preference shaped by dominant norms of publicly acceptable behaviour critiqued in the sociology of mental distress:

...say I'm talking to the voices I might say it out, and people look at you in a strange way, they don't understand you're ill. I found that out. [N]ow, I try and keep it in myself ... I try to keep it in my mind.

Robert described living previously in an area of Glasgow in which he faced abuse from young people that he perceived was related to his mental distress; he could contrast this to the '*nice area*' in which he now lived and felt safe. Ivy was cautious about talking to people about it, citing an incident in which a woman on the bus had said to her: '*people with mental illnesses shouldn't get what they are getting*', meaning benefits. She didn't know that Ivy had mental distress. This incident had made her cautious, although she had '*quite a few*' friends without mental distress. Bridget's neighbours knew that she had a psychiatric history: '*Now and again you get ones calling you loonies an' that... Och that was years ago right enough, I've not heard anything for years*'.

So there was some material evidence of prejudice affecting how participants behaved and impacting on their social circle. For participants this was not a regular experience, but it suggests that people can remember a single incident in their whole life, indicating the power of prejudice which can lead to adaptive preferences (c.f. Watson, 2003).

### 7.5.2 Discrimination

Discrimination was also experienced, distinct from prejudice as stemming from organisations and individuals that held the power to deny socially valued roles. Caroline, a psychiatric nurse, revealed discriminatory attitudes amongst mental health service managers:

...you always try and find out who is your boss, ask around... how are they with these things? Because there's some people who really would



make your life quite difficult... The irony, within mental health... [E]qually there's some people who ... love the concept of 'you've been there, you've walked the walk...'

But '*you've been there, you've walked the walk...*' was revealed as a problematic assumption by Caroline herself as she distinguished herself from others with mental distress:

R: I'm not someone, for example, who has severe, something such as maybe schizophrenia... who might be hearing voices constantly throughout the day, who even though on medicine has still very loud voices and doesn't, isn't able to, participate in daily activities, who doesn't really socialise... isn't able to hold down a job, who isn't ... comfortable in public, has a lot of negative symptoms... [W]ho has a life that's quite limited and is in and out of hospital quite frequently...

I: So that's not you.

R: That's not really the way I am ... and I would quite like it not to be.

This reinforces that stereotypes can also be held by others with mental distress (Warner, 1994, p.181). Caroline's description constitutes a wide collection of characteristics, relying on a normative, decontextualized, individualised, deficit view of mental distress, conflating the internal experiences of a person with what that person might actually be able to do and be in the social world. She demonstrates the difference between using a capabilities focus on what people actually do and be, and a medical focus in which the conflation of internal feelings and external activities results in a tendentious explanatory framework, showing how established medical categorisations can essentialise and create hierarchies, leading to discrimination.

Lara felt that some organisations did not understand subjective mental distress '*as well as they thought*', citing an experience with a mainstream voluntary organisation for young people in which a lack of understanding made her feel unwelcome:

...when I was very down ... a member of staff told me to just get over it and that by now I should really have got it out of my system and move on... And ... when I was too high they basically said that they couldn't deal with me and could I please not come until things had calmed down [laughs]...

So, in socially valued organisations, and in mental health services, participants could experience poor attitudes and their experiences demonstrate how stereotypes can lead to discrimination by people that hold the power to decide who gets socially valued roles, and therefore who experiences social justice. These examples show how people with mental distress can be denied the capability, and therefore also the potential functioning, of being employed or being part of a voluntary group. This demonstrates the iterative relationship between capabilities and functionings. It also shows how using a capabilities analysis reveals that there is a normative choice to be made by institutions and professionals, acting as social Conversion Factors, about whether they support people with mental distress to widen their capabilities in order to enable them to pursue both socially valued activities and personally valued activities.

Lawrence and Steve, with thriving characteristics, in contrast experienced good attitudes from employers. Lawrence's third sector employer held his job open for him for two years when he experienced mental distress, enabling him to take up the post after hospital. Steve's large private sector employer had a strong sickness policy which, alongside his line manager's proactive attitude, ensured that Steve could maintain employment with the Company during a restructure just as he was recovering after psychiatric hospital. These actions had contributed to their achieving social justice and socially valued roles.

Kirsty discussed why, despite her subjective experience of distress at the age of thirteen, she felt fairly treated, taking her explanation beyond mental distress as the 'master status':

...if I maybe was ... from a kind of lower socio-economic background, or if I was a black person ... I might have felt more discriminated against, but ... I feel like I've probably had too much support... I don't feel like people haven't taken me seriously or people haven't cared about my needs ... [M]y mum pushed a lot for me to get help ... other people maybe wouldn't have had the benefit of that.

In capabilities terms, this provides a clue as to why Lawrence and Steve, and to some extent Kirsty too, were able to live 'beyond' discrimination and prejudice, reinforcing Scambler's (2006) critical realist critique of Goffman. Other aspects of their social-structural position such as their potential worth as employees or their parents' level of education - positive structural and social Conversion

Factors - trumped discrimination and prejudice. For Steve and Lawrence they also outweighed their negative personal Conversion Factor of subjective mental distress. Others' experience of social relations with mental distress involved navigating uncertain reactions from organisations, professionals, friends and family. Whilst their social and structural privileges did not give Steve and Lawrence a right not to experience mental distress, they enabled them to get beyond these and the social and structural factors that could detriment others' social justice opportunities.

Participants' material experiences do suggest that their perceptions of prejudice and discrimination are not mere social constructions and that negative social attitudes to mental distress do exist, but they suggest that the experience of these attitudes is the exception rather than the social rule, implying that the cause of social injustice lies beyond 'stigma' (Scambler, 2006).

### **7.5.3 How subjective mental distress can be complicit in others' prejudicial reactions**

The negative impact of the manifestation of subjective mental distress on social relations was noted by several participants. Jack looked '*emaciated*' when he was mentally distressed and abusing substances: '*I looked like a corpse. I knew how I looked. And I knew that peoples' reaction to me was one of fear and disgust*'. He contrasted this to the present in which he was no longer abusing substances and his distress was less overwhelming: '*Now I care very much how I'm seen I care how I'm experienced. I care how I am with people ... how I'm perceived...*' Bridget was embarrassed about what people who had seen how she had acted when mentally distressed thought of her; at various times she had sang to herself, stabbed herself in the stomach and walked around the streets naked with the knife hanging out, and swam naked in the duck pond at the hospital. Sophie explained why her behaviour might have materially alienated some friends:

I had access to Facebook on my phone when I was in hospital... I just had been paranoid and posted pish, oh my God the internet has a lot to answer for... I was at a party and I was going around just being really socially inappropriate ... I was really paranoid and would accuse people of stupid shit... Maybe that's why folk stopped speaking to me, maybe I just tell myself it's because it's stigma! (laughs)

These examples demonstrate transgressions of dominant social norms of behaviour, appearance and conversation. Whilst fitting with Plumb's (1994; 2012) call for expanded social norms they indicate the complexity behind this.

Several participants talked about transgressive incidents when they had been 'high' with mental distress. Monica when high became irritable with '*total strangers*', almost getting into fights. She feared being arrested and imprisoned, aware of the disproportionate numbers of people with mental distress in custody:

... I felt very scared of the outcome of that because if I had lashed out at someone ... I'd have ended up with a prison sentence whereas if I was my normal self I would never dream of lashing out at someone...

She distinguishes 'normal' from her distressed self, and her concern with prison is, she explained, due to the empirical overrepresentation of people with mental distress in the prison system (chapter two).

These suggest that negative social judgment can arise from the expression of subjective distress transgressing dominant social norms, so being 'in public with shame', to misquote Adam Smith (in Sen, 2010, pp.255-256), in ways that suggest limits to the 'dignity of risk' suggested by Hopper (2007, p.877). For others, as seen earlier, prejudice came without a precipitating action, but from reproduction of dominant social norms towards people with mental distress as a group.

In capabilities terms, people with mental distress in these circumstances are behaving with diversity, and performing functionings within a widened capability set, acting transgressively. But this places them at risk of social rejection due to transgression of social norms, reinforced by lack of adequate protection as the prison data suggests. The emergent capabilities and mental distress literature does not yet address this issue which also raises questions for concept of agency.

#### **7.5.4 Disclosure of mental distress**

One indicator of perception of prejudice and discrimination is how disclosure of mental distress is navigated. Several participants contemplated disclosure to

employers. Tim: *'I'm sure the boss would ... say well I'm going to take this guy instead of me because a mental health problem and he hasn't been working for the last four or five years'*. Tim is not only saying it is his mental distress, but also his employment history that will be judged. Lara similarly combined layers of analysis in discussing her perceptions:

...I worry about ... telling ... potential employers because they may have the Disability Discrimination Act but they don't really want somebody with my history ... for me personally if you can't accept that I come with mental health issues you can't accept me as a person ... But when it comes to employers you ... can't just say 'well I'm not going to be friends with you then', you've got to get on with it...

She perceives that employers have expectations of behaviour which she may not be able to fulfil due to her mental distress, a problem that in the informal world of friendship can be navigated with more agency. Similarly to Tim, she sees a difference between the formal legal obligations placed on employers and the dominant normative choices that employers would make beyond that, leaving her in a second class position. Her sense of agency in disclosing is limited to personally valued relationships, not the socially valued world of employment. Both she and Tim perceive that they are also disadvantaged by dominant normative structures in the employment market. In saying this, they implicitly reinforce Scambler's (2006, p.292) critical realist note, that:

...disadvantage sometimes accruing to those regarded as shameful through stigmatization is more often than not mixed in with, even secondary to, exploitation and oppression. It is empirically rare for an individual to be simply stigmatized or exploited or oppressed...

Consideration of social ordering, regulation and governing relations beyond the face-to-face interaction are required for a least reductionist analysis.

The experiences of participants with professional backgrounds illuminate how disclosure processes can operate in a more socially valued context. Lawrence and Steve were able to inform friends without experiencing prejudice or discrimination, even though Steve, with archetypal thriving characteristics, had *'lost my self-respect and felt humiliated'* through the experience of mental distress and hospitalisation. But Steve and Lawrence's navigation of disclosure to

employers differed. Steve's strategy of work disclosure was also to be open, contradicting an offer from his hospital ward to minimise disclosure:

One of the nurses came up to me and said 'we're writing your sick line... do you want me to say it's depression or do you want me to say it's something else?' So ... and I can totally understand it - the nurses were almost saying 'we'll give you the opportunity to make a euphemism.' And I said 'no, no. Put down it's depression.' So ... I never hid it and I've never had any taboo about it '...it's depression, deal with it employer'... [S]o everybody knew... [P]eople would know different levels of detail but there was no covering up...

This suggests how the mental health system can conspire with and reinforce notions of mental distress as an issue of shame or guilt, even if their actions may, as can be conjectured here, be based on experience of people risking discrimination from employers by disclosure through sickness certificates. But they also enabled Steve's agency to decide whether to disclose. Steve's '*people would know different levels of detail*' suggests that the agency to disclose is relational, not binary, even for someone in Steve's thriving position.

In contrast, Lawrence had in the past used his agency not to disclose to an employer in the social sector. But he then experienced subjective distress whilst at work, so the employer found out, reinforcing how mental distress can disrupt agency. He recently gained another job in the social sector and did disclose '*in a positive way*', in part as his experience of the mental health system fitted with the role. But what also made a difference was time, in the previous post:

...I'd been ill pretty recently compared to now. I think even if it was closer to me being unwell I'd be more cautious about declaring it than now, because it's like four years later since I've last been in hospital.

Disclosure was made easier for Lawrence in his recent application as he could position the experience as relevant to the post and hospitalisation was further away temporally, in the process demonstrating strong use of agency.

Francine, in changing her career from the armed services to church ministry, faced a different dilemma. Her subjective distress was at an intense point when she attended interview, so she felt the need and responsibility to disclose, which she felt was reconciled due to the ethos of the work. She did not feel that

disclosure would disadvantage her, demonstrating that even reception of present mental distress can vary according to ethos of employer and job role.

When considered in relation to employment, on which high dominant normative value is placed, these stories demonstrate the strategic diminution and reframing of the experience of mental distress required to disclose safely, in the context of the strong perception and occasional experience of prejudice and discrimination especially impacting on those without previous professional roles. The data show, though, that this is not a universal experience, and may vary by ethos of employer. It also suggests how the mental health system may become drawn in to perpetuating social norms of shame and guilt in this context.

Overall the data on prejudice and discrimination reveals more complexity than contemporary mental health campaigns tend to suggest,<sup>10</sup> so getting beyond stereotypes that can imply that ‘stigma’ is singular, persistent and consistent.

The data also demonstrate that disclosure is relational in terms of adaptive preferences and employment. All the experiences, except that of Steve, show people being structured into making a choice about how to disclose. They base this on awareness of prejudice and discrimination and so have a resultant incentive not to disclose, or to position disclosure with great care, in order to maximise employment capabilities and so gain a socially valued position. However, this is not a simple adaptive preference as Sen suggests it, accepting lower-than-optimal social outcomes, but instead is a positioning of discreditable information, using agency in response to structure, in order to stand a realistic chance of gaining that socially valued position. The underlying problem is not of settling for a second-best ultimate outcome, but having to adapt the free will to disclose in order to have a chance of gaining the most socially valued outcome: a means to an end.

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<sup>10</sup> e.g. [www.seemescotland.org/](http://www.seemescotland.org/), sourced 31 March 2015

## **7.6 Education, employment, income and social justice**

### **7.6.1 Introduction**

This section draws on data that documents participants' experiences in three socially valued (Hopper, 2007, p.874) areas of life: education, employment and income. These are selected as empirical data show that people with mental distress tend to have lower educational outcomes and opportunities than average, and far fewer opportunities for employment (Chapter two). The lower incomes resulting from these gaps have the potential to further impact on social justice.

By exploring education and employment, this section reveals how agency is shaped in the context of social and structural Conversion Factors in these socially valued settings. People may volunteer, do supported employment or do particular jobs or courses for what might be sub-optimal reasons, revealing 'adaptive preferences' in relation to social justice, with capabilities unfulfilled and social justice denied. However, for some participants their opportunities in education and work were more optimal. The open-ended character of the interviews allowed participants to reveal their subjective contentment with what they were doing, and aspired to do, therefore enabling the analysis to combine the subjective and objective.

### **7.6.2 Education and social justice**

In terms of educational background, the sample was diverse. Several participants did not have a higher education qualification (Arthur, Robert, Bridget, Gary, Ivy, Jim, Lara, Tim). Several had a higher education qualification (Martin, Lawrence, Monica, Steve, Francine, Caroline). Several participants had their school education negatively affected by mental distress (Kirsty, Bridget, Lara and Caroline). Several were currently in higher education and experiencing mental distress (Francine, Sophie, Kirsty, Becky).

Most participants had been in education as adults whilst also experiencing mental distress. Some had done courses aimed specifically at people with mental distress, sometimes provided by the mental health voluntary sector (e.g., Ivy, Martin, Monica, Barbara, Tim). Others had done mainstream college courses



(e.g. Gary, Lawrence, Steve), some doing both over time. Participants talked about several aspects of using mainstream and specialist education.

Participants found mainstream education meaningful in various ways. First, as a means to demonstrate personal competence in the context of mental distress disrupting past education, for example Sophie:

I did Sociology and Psychology on the [University] access course... I got, like the prize for it ... I had to drop out of uni because I went straight from school to study radiotherapy ... and I was just so mentally ill I was getting shit marks, so when I got that [prize] I was like 'hooray! Not stupid after all'.

Second, becoming part of a routine or structure during mental distress, the educational subject being less important, as Lawrence experienced:

I was on IB [Incapacity Benefit] for 18 months ... no-one ever suggested you know do some voluntary work... It was my parents who said you need to get a bit of structure, um, do some short courses, I was on benefits get them for free so go to guitar lessons... Spanish lessons... photography classes ... it was something that I really had to force myself to do ... but probably the most important thing was the structure...

Third, being with other people, for example, Robert was currently unable to attend his course due to the withdrawal of his travel pass: *'it's just the fact I can't get back to college that really murders me, I don't know what to do because I've got a lot of really good pals at college ... a good laugh'*.

Analysed using capabilities, these each reveal limits: Sophie seeing the personal Conversion Factor of subjective mental distress limit her achievement on her radiotherapy course; Lawrence relying on his parents, rather than mental health service providers, to act as social Conversion Factors encouraging him to do short courses; and Robert's frustration that a social Conversion Factor, the changing policies of the Transport Authority made it unaffordable for him to attend college. They also demonstrate the dynamic way in which education acted as a positive social Conversion Factor helping to expand capabilities of knowledge (Sophie), managing mental distress (Lawrence) and affiliation (Robert). A capabilities analysis therefore enables a structuring of data to explain how structural, social and personal factors shaped access to and impact of education.

These data also contribute to the debate emerging in this chapter about whether functionings or capabilities are important to a capabilities evaluation of social justice for people with mental distress. In these three examples, as earlier, it was the actual doing - the functioning - not the substantive choice of doing (the capability) that mattered in demonstrating academic competence (Sophie), providing structure (Lawrence) and experiencing social life (Robert). However, the capability set available to the individuals needed to include these particular functionings that had meaning to the individuals in order for the functionings to be enacted: whilst the functioning may be 'in the last instance' the arbiter of social justice or injustice in a particular domain, the two cannot be analytically separated and in practice are entwined.

But education could act as a limiter for people with mental distress. Despite his desire to do paid work, Martin's functionings had become a roundabout of courses:

I have a lot of choice now because I've got some educational qualifications behind me ... and I've done umpteen courses in computing and French, I've done SVQ in Gardening, I've been trained to use tools and metalwork ...

In many ways he is in a 'predicament' (Barham and Hayward, 1991). As seen earlier, his real desire, a '*decent job that pays well*' is not on offer, leaving him with a very limited capability set.

The data raise a question about whether widened capability sets may be best achieved by specialist or mainstream education, echoing the earlier discussion about specialist groups. Jon gained support from a homelessness charity when his mental distress was difficult:

That's when I got back into groups. They had ... skills and resettlement training... [T]hen I done the ECDL and really since about the past eight year I've been working myself up, educating myself again.

He had continued with mainstream education at higher levels, whilst still managing his mental distress, showing how, as with his art therapy, the short-term specialist support to convert a capability, such as to be in groups, could lead to a longer-term functioning expansion. However, he was currently finding

the behaviours of some others in mainstream classes disruptive to his mental distress, acting as a negative social Conversion Factor. This indicates the need for advances in understanding capabilities temporally (Wolff and deShalit, 2007).

Tim had experienced both specialist and generic education and found that whilst mainstream threatened his functionings, specialist nurtured his capabilities:

Most of the classes I go to are people with similar situations to me and there is a comfortability there... [T]he mainstream classes ... really freaked me out... probably some of the people in the classes have been through mental illness... But there was this thing of feeling a complete outsider, being a fish out of water... And there was pressure... [T]he classes ... specifically for people with mental ill health ... if you are feeling a bit ... 'I'm not good enough for this class' well at least you know all these people are kind of in the same boat ... and that kind of spurs you on ... [A]nd ... the teachers, they've kind of been trained ... to work with people with mental illness. Now that's not to say that the tutors at [mainstream college] aren't, it's just that I didn't know...

So a specialist class provided Tim with greater confidence in the tutors' understanding of mental distress, of belonging to a peer group, and feeling less pressure to perform, giving him more confidence in his abilities. He was not insensitive to the possibility that mainstream tutors may understand mental distress, or that other students in the mainstream class may have personal experience. But in the mental health-specific class he felt more confident in maintaining a threshold of educational achievement as the teaching context was less disruptive to his mental distress. This shows how for Tim, mainstream education as a social Conversion Factor threatened a functioning, whilst the mental health-specific class as a social Conversion Factor nurtured his capabilities. In this case, capabilities analysis shows that specialist classes as social Conversion Factors can be an effective means to the end of maintaining functionings for people with mental distress, whilst showing that mainstream classes need to do more to remove barriers and so open potential for social justice.

However, several participants preferred mainstream courses, including university, whilst experiencing mental distress. They described the tensions involved in navigating this. Subjective distress could be offset by the motivation to physically leave the house to attend, meeting others with the same interests,

and by support from university Disability and Counselling Services, and empathetic subject teachers, university facilitating a range of positive social Conversion Factors. But this was sometimes opposed by the pressure of course deadlines, a negative social Conversion Factor, which could increase mental distress. And this was shaped within a structural context in which students were aware of the potential social benefits of gaining a university qualification, for example to study a subject for academic purposes and personal fulfilment (Kirsty) or as a means to an end such as changing career (Francine). So, converting a capability to pursue mainstream education into a functioning, whilst experiencing mental distress, involved a complex navigation.

So whilst specialist education can develop capabilities, some people end up on a roundabout of courses, not widening their capability set, but maintaining a threshold of functionings. Participants took mainstream courses and these could help to widen functionings, but involved navigation of positive and negative social Conversion Factors. For some, like Tim, this was too stressful, and specialist education provided a better route to maintaining functionings, but with ambiguous social justice outcomes. There is a social gradient in evidence here, as participants without a background in higher education, such as Jon, struggled to navigate their way both into and then through mainstream higher education.

### **7.6.3 Employment and social justice**

In terms of employment, discounting the participants in their twenties whose working lives were still emergent, past and present functionings diverged. Some participants had been in paid mainstream employment through long periods of their life (e.g. Francine, Gary, Harry, Monica, Steve). These participants first experienced significant mental distress as mature adults, which had then affected their employment functionings either on an ongoing basis (Gary, Harry, Monica) or temporarily (Francine and Steve). Steve and Lawrence were the only participants currently in mainstream employment.

Several participants over age thirty had first experienced significant subjective mental distress by their early twenties, and had hardly worked in any mainstream employment in their lives. Arthur and Martin, and also Fiona, had

worked in supported employment through mental health organisations, and were currently still doing this, and Jack was currently in temporary employment with a mental health organisation. Following Nussbaum's (2006) argument in relation to disabled people, the dominant norms structuring paid mainstream employment excluded some people with mental distress, a negative structural Conversion Factor running through the data.

People talked about employment and mental distress in a variety of ways. In terms of past work functionings, people had to stop mainstream employment for a variety of reasons, most commonly related to their subjective distress stopping them continuing the same job. Bridget had hallucinations at work, Lawrence bipolar episodes, and Francine depressive feelings. Each was apparently not caused by the work activity itself, but was experienced as non-compatible with their work, for example for Francine, also displaying the power of behavioural norms in the armed services:

...it's just not appropriate for somebody - an officer - to be walking round a base with tears streaming down her face. Or there were days where I felt I couldn't put my uniform on because I felt that I was betraying what that uniform stood for.

Some participants did see employment itself as triggering subjective distress; Harry and Steve attributed their mental distress as due to overwork. Caroline's situation was affected by other stress features at work. On qualifying as a psychiatric nurse, she was appointed as team leader in a private sector community mental health team. She faced animosity from the existing staff due to being young and promoted ahead of them, and her boss then sent '*very very inappropriate*' text messages to her and a colleague. The other staff member reported him and he was dismissed, but her team interpreted the incident as if she had been appointed because she had a sexual relationship with him. She could have coped with the stress of the staff issues but the texting made the difference and '*within four months the stress levels got too high, all my symptoms came back and I was signed off sick*'. This suggests that it was intersectionality between gender relations and mental distress that made a difference to Caroline maintaining this socially valued role.

These tensions between mental distress and the workplace are interactions of the personal and the social-structural; the social affecting the personal either as a causal factor or as a factor that casts normative judgment on acceptable behaviours. They exemplify Plumb's (1994; 2012) distinction between the need to minimise social triggers for mental distress and the need for society to become more accepting of diversity in subjective behaviours in order that people with mental distress not be excluded in the first instance.

The comparable employment positions of Arthur and Steve demonstrated how different social justice outcomes are shaped by experiencing mental distress in the context of 'the normative concerns of the social order' (Rogers and Pilgrim, 2003, p.181). At his first interview, Arthur described how his capability to move from supported employment to mainstream employment was shaped by medical advice about how his subjective distress could constrain his ability to do things in particular social environments:

I would like a full-time job. The doctor says I can't do it... every year I think I'm getting better because of medication and every year she says 'you cannae go to work the now' ... I used to pick up voices so the doctors don't want me to go to work and pick all those voices up... I don't think I'm going to get a full-time job but that would be a dream come true.

By his second interview, an incident at his supported employment project in which he needed help with shovelling and was '*knackered*' had led to Arthur changing his position:

...the psychiatrist is right ... I couldn't ... handle the pressure of a full time job ... I'm not going to be able to work... [but] I can still go and do volunteer things ... three times a week, a couple of hours a day ... so that's fine with me at present.

In interview one Arthur wanted paid work; in Interview two voluntary work was sufficient, in capabilities terms an adaptive preference. But Arthur and his medical team had self-limited his capability set, demonstrating their mutual limited conception of possible jobs - not all involve physical fitness. Arthur's doctors, as social Conversion Factors, had an internalised conception of mainstream employment as unsuitable for Arthur, constraining him from fulfilling his capability to work, in order to reduce the possibility of reoccurrence

of distress. In capabilities terms, this raises the question, parallel to the role of constraining functionings in hospital, of whether this medical position of constraining Arthur's capabilities is actually enabling one current 'fertile functioning' (Wolff and deShalit, 2007, pp.120-122), health, that may be the basis for future others. The problem is that Martin and other participants with surviving characteristics have shown that this can lead to a roundabout of courses and supported employment, denying them a socially valued position, leaving the structures that shape employment norms in place, and therefore people with mental distress lacking social justice.

It is possible, though, that Arthur was at the limit of his capability set and unable to cope with mainstream employment in part due to his many years of mental distress. This would reinforce Nussbaum's (2006) foundational argument of the need to be a particular type of human to be a mainstream employee - reliable and profitable - following the norms established by the social contract.

In contrast, Steve held a very senior role in a large company with 'very good' sickness policies and a manager that wanted to keep him during a restructure despite his being hospitalised for seven weeks after feeling suicidal:

...my boss had come out to my house one night and said 'there's a job that's ... right up your street and I think you should apply.' And I did, even though I was very fragile at that time ... it sort of paved the way for where I am today... [I]t was only five or six short weeks before that I was thinking 'I'm doing basket weaving for the rest of my career.'

Steve, covered by sick pay, had time to pursue therapeutic activities in between being in hospital and returning to work. He returned to what he described as a 'challenging' post, comparable to his previous role. He exudes confidence about his career now and about the place of mental distress in his life, embodying agency in both areas. Although he experienced mental distress as a negative personal Conversion Factor, positive social and structural Conversion Factors outweighed this. He did not experience social injustice in employment. He may have experienced mental distress, but this did not define his social justice, revealing the weakness of taking mental distress as a defining characteristic, towards which survivor-influenced studies can tend (Chapter two).

The way in which ‘the normative concerns of the social order’ (Rogers and Pilgrim, 2003, p.181) lead to employment being socially valued - and non-employment not - was also revealed in the data. Gary's past employment functionings, in factory and driving jobs as well as periods of unemployment, had not been personally valued by him. But his mental distress had offered him a glimpse at a new capability set, being free not to work and to pursue creative and therapeutic activities instead, with the worst scenario being going back to the same type of unsatisfying work:

...you get quite a lot of freedom when you're mentally ill because your sick ticket's out in years... I've got the freedom to come in here and play a drum and ... make a bike and then suddenly you get that [job] interview and it can be all just snatched away fae you, you're back in the rut, thirty quid a week and your vision is a cleaning job doon at the shopping centre ... that is not what I want tae be looking at in six months but they think that's good ... I think that looks bloody as if I'm going to be back in [psychiatric hospital] in six months [laughs]...

Gary had a probation officer who aimed to get him into work as a fork-lift driver comparable to the factory jobs he held before his suicide attempt. She was revisiting his old capability set. But he now saw a new set of capabilities as possible, opened up by experiencing music therapy and bicycle repair activity, alongside a realisation that his old work environment stimulated his mental distress. He wished to continue attending these groups hoping to ultimately expand his capabilities into new work areas such as working with music and sound. So his desire to widen his capabilities was in conflict with his probation officer's desire to return him to the same work area, maintaining his functionings. Gary is in a position of ‘being outside’, not valuing employment *per se* as it can involve suffering not flourishing, so contradicting its dominant normative position as a socially valued activity.

Similarly, at Interview Two Becky had left a university course that she was not happy with, had resigned from a job that she felt unethical, and had also sought a capability set outside the dominant norm. She had started singing lessons. They ‘*are expensive*’ but feel right, her social Conversion Factors supporting her agency:

I know that if I don't do it I sit at home going oh God I'm twenty-six and I should be doing my dream, I should be living what I want to do ... and



because I've moved home I can just feel this kind of sense of security that I can do it.

However, she felt '*quite nervous*' about meeting certain friends who might ask what is she studying and what job is she going to do, demonstrating the agency required to deviate from the dominant social norm. But she and Gary also reveal how the dominant norm can create personal pressure to conform by state actors or friends, demonstrating how social reproduction happens.

Gary's experiences help to reflect on those that tend towards surviving, like Arthur, Bridget, Martin and Robert, all on benefits but who, had they been structured into mainstream employment, may have similarly suffered. This follows Sayer's critique of capabilities (2012) that satisfying work is unequally structured and that unequal divisions of labour are a major cause of capability inequalities. So whilst former professionals like Steve had their functionings reduced by mental distress, Gary's example demonstrates that for people in non-professional work a new capability set can be opened up by the social relations that follow experience of mental distress. Gary's case exemplifies how working as a fork-lift driver is more socially valued than attending voluntary groups for people with mental distress. Gary personally values the latter, reflecting the capabilities principle of diversity, but the state values the former, alienated labour being more socially valued than non-alienated participation in a voluntary group.

Gary and Becky exemplify how a capabilities approach adds to the analysis allowing a move beyond functionings. It allows the analysis to account for peoples' diversity, doing and being things that are not necessarily socially valued, but which are of personal value. They show how widening the capability set may conflict with dominant social norms, and therefore set up a challenge for professionals operating as social Conversion Factors such as social workers, probation officers, social care and support services, and the social security system more widely, in considering how they support people to pursue personally valued functionings that may, for example, challenge the dominant social norm that 'work is good'. The normativity of the capabilities framework allows this analytical breadth.

These employment experiences also offer further commentary on the relational character of adaptive preferences. Arthur, with his medical team, limited his option of starting work in order to secure health, but in the context of a limited view of work possibilities; Steve did not adapt his preferences after psychiatric hospital, continuing his preferences; and Gary and Becky widened their capability sets after experiencing mental distress in order to escape unwanted functionings. They did not all therefore adapt their preferences in a single, more limited, direction, despite their experiences of mental distress. These reinforce the complexity that lies beneath the concept and the need for further research to distinguish the value of the concept to a capabilities interpretation of social justice.

The missing layer in employment narratives is that of the underlying causal mechanisms, theorised in Critical Realism. These structure the character of paid work, resulting in it being seen, for example by both Arthur's medical team and Arthur, as inherently unhelpful to his mental distress, rather than as a range of possibilities of different environments, levels of support, hours of work and so on, or a system with an obligation to make reasonable adjustments appropriately. It can also be argued that Arthur's team see the brutality of the employment market as Sayer (2012) and Dean (2009) see it, and offer Arthur protection. However, for some participants their employment functionings were missing for years, and sometimes decades, by the mismatch between mental distress and employment norms.

Gary and Arthur fear that going to work will negatively affect their equilibrium with mental distress. This reinforces the problem of how dominant social norms may be changed so as to facilitate the use of agency to withdraw from activities such as work, reiterating the question of how outcomes outside dominant normative activities can be nurtured.

#### **7.6.4 How personal income acts as a social Conversion Factor influencing social justice**

What people experiencing mental distress are able to do is also shaped by the income that they have, acting as a social Conversion Factor and reinforcing the capabilities argument that resources need to be included in the analysis of what

people are actually able to do and be. Sen makes it clear that income matters absolutely and fundamentally to freedom and wellbeing, since ‘lack of income can be a principal reason for a person’s capability deprivation’ (1999, p.87; see also 1999, p.72; 1992, p.116). Further, Sen (1992, p.115, his emphases) proposes that: ‘*Relative deprivation in the space of incomes can yield absolute deprivation in the space of capabilities*’. This reinforces how capabilities widens narrow considerations of income deprivation into thinking about what income inequality means in terms of what people can do and be.

Almost all participants spoke about the influence of money on what they could do both in terms of managing subjective mental distress and in terms of pursuing autonomous activities, the data overlapping with discussion on employment. Money strongly constrained participants that held surviving characteristics, but barely affected the minority tending towards thriving characteristics. Steve and Lawrence both had full-time professional jobs. For Harry, his distress restricted him mainly to his house, so he did not use much money and could live adequately on benefits. He felt they were ‘*quite generous*’ as long as people did not drink, smoke or gamble, and could budget. However, Harry also had ‘*residual capital from my past life*’, a social Conversion Factor placing him in a more thriving position in this domain.

Sophie was on high rate DLA when she was ‘*really unwell, but I didn’t go out ever so it kind of all added up, so I’ve got some money left*’. She continued to receive DLA whilst at university, finding it ‘*handy so if I’m having a bad day I can get a taxi into uni if I’m a bit paranoid about the buses*’. It supported her to do her university course, the positive social Conversion Factor of money offsetting the negative personal Conversion Factor of mental distress.

For the majority of participants, most of whom were on benefits, money was a constraint, the language used reflecting the compromises on freedom made: ‘*you get there*’ (Bridget), ‘*you cut your cloth*’ (Robert and Monica). Jon talked about the interaction between wanting to do hillwalking to support his mental health and the way in which money considerations constrained this:

...when it’s not too far it’s ok to drive because of the petrol, but you don’t want to be going too far on your own if you can get a lift or get

some people to go in your car, try and cut the cost. So because of that it's not always easy...

Benefit reviews, a current UK Government policy affecting people on long-term sickness-related benefit, were a source of added anxiety for Tim, Monica, Ivy, Fiona and Gary. They all had access to networks to support them in navigating the process, but as Monica noted:

I've just gone on to Employment Support Allowance so I've been through the trauma of being assessed ... so I think that's me for another year, and then I have to be assessed again... the whole process is a nightmare. I don't cope well with paperwork... [T]hey've got to have some way of assessing people but I don't think they have a very fair system...

There is a sense of stress and disruption to equilibrium that does not affect, for example, Bridget who was confident that she would be on benefit for life, or Harry with his underpinning safety net, that mirrors the disruption to equilibrium experienced by Gary above in terms of normative expectations around work. But there is also a sense of unfairness, expressed by Fiona and Gary who were affected by the Spare Room subsidy or 'Bedroom Tax', another current UK Government policy reducing Housing Benefit for families living in social housing with a spare bedroom, forcing them to either move to a smaller house or pay extra for their spare room. Both participants noted that the spare rooms were regularly used for family members to stay. The data suggested that this policy, as with the policy to review benefits, disrupts the equilibrium of people with mental distress, making opportunities for pursuing social valued activities like living family life harder to achieve.

Tim, who worked until his mental distress became significant about five years ago, discussed the potential impact on his functionings, including being with his young son who stayed at weekends, if his money was reduced at his forthcoming benefits review:

...because I get middle rate [DLA] I have my travel card... if I go to three [mental health organisation] classes, [drama group], that's going to cost ... twelve pound maybe. And then ... getting ... to [town] on the train and bus for myself, and then paying for myself ... and [son] to get back. And then [return journeys]. So you're talking ... thirty-five pound a week... so if I didn't have this travel card I'd be snookered. And the only reason I get this travel card is because of DLA...

The travel card acted as a social Conversion Factor, allowing Tim to lead a fuller life, doing social activities that minimised his mental distress and enabled him to fulfil family life. But, as for Gary and Fiona and the Bedroom Tax, a change to Tim's DLA would negatively affect these.

Robert had already had a dimension of his quality of life removed by this type of a benefit change. He enjoyed drama classes which he had to stop as his free travel pass was not renewed and he could not afford the travel costs. He was devastated:

...it's just the fact I can't get back to college that really murders me... I've got a lot of really good pals at college ... I thought the transport maybe would see you're doing something with your life... I was trying to better myself and try to get away from anxiety and depression and things like that... And then to run into that really kind of angered me...

The removal of the travel pass as a social Conversion Factor had led to his agency being frustrated, the functioning of college reverting to a capability. He still experienced anxiety-depression, phoning Breathing Space helpline two or three times a week, the removal of a relatively low-cost positive social Conversion Factor, risking exacerbating his mental distress.

The influence of money on what people are able to do also raises the question of achieving socially valued activities such as employment and housing status. Francine worked in the armed services for eight years. As seen earlier, she had left her job in part due to a perceived conflict between her mental distress and the implied expectations of her role, and was still trying to secure her pension from this post. She talked about the importance of this, and of money more widely, in terms of having some stability:

... if I could be successful in my appeal for my pension ... that would mean that I don't have to worry about anything financial, and it means I don't have to think about [losing] my flat. Because I think if I was forced to move back in with my parents that really would be the end of it... [I]f I was getting a minimum amount of money to pay my mortgage, cover my bills... I'd be happy. It wouldn't make me well, clearly, but it would be one weight off my mind...

Francine follows Sen (1992, p.113) in saying that money alone would not resolve what she could do and be, but argues that reliable resources help to secure

personally important functionings such as living independently, resonant with Wolff and deShalit's 'fertile functionings' (2007, pp.65-72), so reducing factors that may disrupt her mental health. She does not have big demands in terms of what she wants to do in her life, but is trapped (Estroff, 1981).

The experience of people with surviving characteristics is that doings were affected strongly by the social-structural Conversion Factor of money, living on benefits in particular constraining what people were able to do and be, unless their mental distress confined them to the home. The current context of benefit reviews disrupts equilibrium, and the removal of related items such as travel passes seemed to have a disproportionate negative impact on beings and doings, demonstrating Sen's point that it is not just about resources but what people are able to do with those resources - like attend college or pursue family life - that matters. Only a few participants were free of the constraint of money shaping what they were able to do, notably people with thriving characteristics in professional jobs.

## **7.7 Chapter conclusion: how living in society influences social justice for people with mental distress**

The chapter findings are reviewed and critically analysed in the discussion chapter, but a few observations are salient at this stage.

Whilst the data showed that subjective mental distress needs to be treated as a material consideration in evaluating social justice, viewing peoples' experiences through a capabilities lens demonstrated that social justice is shaped by more than distress alone. The limitations of medical interventions to resolve mental distress led participants, once outside the statutory mental health system, to use their agency, interacting with social Conversion Factors, to pursue activities and routines that sought to further manage subjective distress. For some, this included mental health voluntary organisations; others tended to use mainstream groups. These were revealed as indicators of whether people were likely to tend towards surviving or thriving, or their social justice outcomes.

Family and intimate relations, and prejudice and discrimination acted as social Conversion Factors for participants, impacting on their mental distress, agency

and capabilities, and thus on their social justice. Characteristics of surviving, thriving and being outside were again influenced by these social relations, which were encompassed by social structures reproducing categories of power. The achievement of 'recovery' could change people in unexpected ways which could disrupt family relations. Intimate relations could provide an opportunity to demonstrate caring with mental distress.

Participants internalised assumptions of stigma, a singular experience having a high salience. Discrimination and prejudice could happen in response to the expression of subjective distress challenging social norms of behaviour, adding complexity to understanding of prejudice and discrimination and reinforcing Scheff (1966) and Goffman (1990). Professional participants demonstrated the strategic work required to disclose mental distress 'positively' in the context of employment.

Some people with mental distress were seen to live with the persistent threat of being re-placed into a distressing world through work expectations and benefit reviews. This suggests that for some people with mental distress, social justice is best secured by having social security in the form of balance and equilibrium, unthreatened, and their agency to choose capability sets that do not include personally stressful but socially valued employment, enabled.

Five observations specify how using capabilities to interpret social justice enables critique of existing concepts and normative assumptions from social understandings of mental distress, and shows how using capabilities as an analytical framework for empirical data enables critique of concepts in the capabilities approach.

In terms of critique of social understandings of mental distress, first, as seen in Steve's example, even for a person with thriving characteristics, social relations within the family can be challenged by 'recovery' from mental distress: a notable qualification to the dominant recovery model.

Second, the expression of subjective mental distress is socially shaped and mental distress socially shapes, for example to what extent people feel able to pursue mainstream activities, or stimulating particular social responses from

others. Mental distress therefore is inherently social and cannot be detached from the social-structural context that enables or constrains agency to pursue socially valued activities. As Scambler (2006) in his critical realist analysis implies, two people with the same 'order' of subjective distress may experience very different outcomes, related to their position in the social-structural context. This suggests that Tew's mental distress as disruption of agency (2011, p.29) therefore risks falling into the trap which Sayer (2012) identifies, and for which Venkatapuram (2012, p.154) critiques Nussbaum, of treating external conditions and internal capabilities as if they are discrete when they are complicit.

Third, in terms of the capabilities versus functionings debate, understanding what people actually do, or their functionings, does offer a 'last instance' arbiter or measure of social justice. However, the ability to convert capabilities into functionings by the participants in this study has been strongly contextual. On the other hand, for this sample, drawing conclusions about social justice outcomes on the basis of capabilities alone provides an inadequate measure, as their ability to convert capabilities into functionings is contingent on so many factors. As seen in this chapter, these can include subjective mental distress, the supportive (or otherwise) context of a workplace, the roles of professionals and organisations that are social Conversion Factors, and the dominant social norms which underpin who is seen as a suitable person to achieve a socially valued role. It would therefore be an analytical error to draw conclusions about social justice outcomes on the basis of either functionings or capabilities as both are relational. However, it can be seen that capabilities are essential to bring into the analysis, as it is these on which functionings rest. This demonstrates the added value of capabilities for analysis of social justice both in theory and in practice. This theme merits further research beyond this thesis.

Fourth, established assumptions in the sociology of mental distress of the impact of social stigma are muddled by the data, in a way which advances Tew's (2011) 'triple whammy' model. For people with thriving characteristics, the evidence suggests that discrimination and prejudice figure only as marginal, because for people from a more highly educated and professional background, discrimination and prejudice are less likely to have - and therefore be perceived as having - an impact on their socially valued status. For people with surviving characteristics,



however, discrimination and prejudice towards mental distress are perceived as more central in explaining their difficulty in establishing themselves in socially valued positions. But the objective explanatory factor is that employment norms are structured in such a way as to favour certain groups for the few socially valued employment roles that exist (Sayer, 2012). Socially advantaged people with mental distress are more likely to attain socially valued roles. The experience is not equal due to structural and social Conversion Factors, of which discrimination and prejudice - stigma - play only a part.

Fifth, the capabilities concept of adaptive preferences has been developed in this chapter. The lived experiences demonstrate that, when interpreted using Sen's notion of adaptive preferences, the underpinnings of the concept are too binary and lack relationality. Participants demonstrated how diverse adaptation can be, contingent on agency and on relational circumstances. They showed how lives change over time, and how adaptation can take the form of self-preservation in order to maximise the chances of achieving socially valued functionings such as health and work.

## 8 Social justice re-worked: the domains approach to capabilities

### 8.1 Introduction

The first three chapters have conceptualised how experiencing subjective mental distress, using the mental health system and living in society with mental distress, all shaped by dominant social norms related to mental distress, interrelate; and how these shape social justice outcomes, so ‘attempting to reconceptualise mental distress within a social framework’ (paraphrasing Beresford, 2010, p.57). It has achieved this by developing and applying sociologically theorised capabilities concepts, and then by inducing data from semi-structured interviews. This inductive method is compatible with Sen’s open approach to capabilities analysis, on the basis that an underlying idea such as quality of life has an ‘essential ambiguity’ methodologically, which must be captured (1993, pp.33-34).

Nussbaum’s most distinctive contribution to capabilities has been the development of a list of central human capabilities (‘domains’) whose specification and thresholds are for local debate and elaboration (see chapter three), which, when upheld, underpin the achievement of social justice. Whilst this participatory dimension is compatible with Sen’s work (Nussbaum, 2003, p.44), he famously remains cautious about endorsing any account of central human capabilities. However, Nussbaum argues that without a list of central human capabilities (‘domains’) we are condemned to eternal relativism, left ‘in limbo’ (2003, p.44). Instead (2003, p.56):

To get a vision of social justice that will have the requisite critical force and definiteness to direct social policy, we need to have an account, for political purposes of what the central human capabilities are, even if we know that this account will always be contested and remade.

This chapter describes participants’ responses deduced from the stage two interviews which, after starting with an ‘update’ conversation from the first interview (data in chapters five, six and seven), were structured using a closely adapted version of Burchardt and Vizard’s (2011) list of domains, each exemplified by several sub-examples (2011, pp.116-119). These were adapted

from the work of Nussbaum and from consultation with groups experiencing social injustice, but not including people with mental distress. Their domains were boosted for this exercise with two of Nussbaum's domains ('Play' and 'Other species' from 2006, pp.76-77) relegated by Burchardt and Vizard (2011), but highlighted by participants in the stage one interviews, providing a participatory dimension (Tew et al, 2006). Burchardt and Vizard identified people with mental distress as a priority disaggregation group that they had not reached (2011, p.99) and so this study provided an opportunity to develop their method and findings. The approach taken was also influenced by that of Wolff and deShalit (2007), but again applied in the original context of mental distress.

The earlier chapters thus gained a 'bottom up', or more Senian view of what people with mental distress were able to do and be. This chapter takes a more Nussbaumian approach, exploring how capabilities domains emerging from consultation with other groups experiencing social injustice may 'speak' to people with mental distress, offering them a means to critique, amend or expand these. This process allows consideration of whether people might say that different things were most important to social justice when using a Nussbaumian domains approach as a starting point, compared to those emerging from the more inductive, Senian approach.

The chapter has three aims. First, to address an identified empirical gap for capabilities by illuminating how people with mental distress respond to the domains. Second, to understand how data deduced by using the domains approach as a method illuminates data induced in the stage one interviews. Third, to show how empirical work using the domains approach as a method with this social group may inform ongoing debates within the capabilities philosophy including ontological and methodological critiques of the domains method and contribution to whether capabilities or functionings are the appropriate measure of achievement of social justice. The chapter concludes with a discussion of the chapter findings, including consideration of how useful the domains approach is as a method for framing and interpreting qualitative data and understanding social justice for people with mental distress.

The interviews generated a large amount of data, interpreted as described in the methodology (chapter four). For reasons of space, only some of the findings

are presented here, those most salient in providing commentary on interpreting social justice outcomes for people with mental distress using this method, and those which inform ongoing debates on the domains approach to capabilities as a philosophy and method. Whilst the data are highly truncated by the researcher, this is done in explicit ways, responding to a weakness of Wolff and deShalit (2007; also see Chapter four) indicating, for example, the density and spread of comments.

## 8.2 Overview of the data

Eight male and eight female participants took part in second interviews. Those who did not were Barbara, Gary, Ivy, Jack, Sophie and Tim. Barbara was in hospital, Gary and Ivy did not respond to requests, Jack could not be traced, and Sophie and Tim initially said that they would participate, but this did not transpire. Barbara had learning disabilities, so her participation would have enabled a specific perspective on the domains.

Of sixteen interviewees, fourteen commented on the being healthy domain (see diagrams, Appendix eight), thirteen on being yourself and twelve on enjoying a comfortable standard of living. Being healthy had easily the highest number of Nvivo codes (26, the next highest being yourself with 17). A minority of respondents spoke about living in physical security, avoiding premature death and relating to animals, plants and the world of nature. It is striking that being able to laugh, play and enjoy recreational activities was spoken about in detail by several participants, given that it was omitted as a domain in itself by Burchardt and Vizard (2011).

Twelve participants responded to the 'anything else' box, engendering a more participatory approach to the domains. Most participants brought in complexity across the domains or queried the basis of the domains, including in terms of conceptualising a thriving life. Most also argued that some domains were more salient than others, or argued that the achievements of some domains rested on the prior achievement of others, reinforcing Wolff and deShalit's (2007) concept of fertile functionings. Half talked about whether it was the capability or the functioning that mattered to thriving, and, reflecting the capabilities literature, this was complex to operationalise. As with Wolff and deShalit (2007),

participants mainly spoke in terms of their individual experience, providing the benefit of subjective data on experiences of breach of thresholds. Whilst only four participants were explicit that thresholds had been breached for them, all others stated this implicitly.

The diagram and domains seemed to fit participants' intuitions (*'thought-provoking'*, *'hard to think what's missing'*), an important consideration for this type of exercise (Wolff and deShalit, 2007, p.43). No-one struggled to understand the basic intent of the domains, the qualities being what people should have all of in order to thrive; it was in the interpretation and ambiguity below the domain headings that issues emerged.

Whilst finding the domains clear, Fiona identified a discriminant validity problem, which emerged further through the analysis:

It explained itself every block. There was like room for different answers but some I felt ran into each other but they were self-explanatory like I felt they were easy enough to answer.

In Burchardt and Vizard's list (2011, pp.116-119) several sub-examples appear in more than one domain, there being no reflection on discriminant validity. This is important because if the domains are in some way intended to measure the achievement of central freedoms, lack of achievement of the same sub-example might impact on two or more domains. This may be appropriate in reflecting how life actually is, for example 'care for others' can be both a productive and valued activity and part of enjoying individual, family and social life, and if a person is deprived of an opportunity to care, both these domains may be harmed. But this necessary complexity may reduce transparency and increase subjectivity: who is to judge the extent to which an example within a domain needs to be breached in order for the domain itself to be breached?

Francine argued that *'the sources are more medical based I would imagine...'* This reflects Wolff and deShalit's critique of Nussbaum's domains conceptualisation - understating the relational, caring dimension which elsewhere is pivotal to her philosophical writing (2007, p.45). But as seen below, for several participants the process revealed an original means of conceptualising the structural, social and personal relations of mental distress.

Arthur found the interviews useful as they were *'not all about the illness'* and kept a copy of the diagram as he felt that it would help his wife to consider the wider aspects of life that he felt could be useful for her to consider in managing her mental distress. This suggests a lay operationalisability to the domains model.

### 8.3 Perceptions of thriving

In order to provide a subjective starting point, and to draw out any contrasts between subjective thriving and deduced lack of social justice indicated through the domains, participants were first asked whether they were currently thriving or 'getting by' (see Interview Two schedule, Appendix six). Steve and Lawrence were unequivocally thriving, reflecting the data in the first three chapters.

Steve: *'I would say more so than before [my distress experience] ... a more rounded ... person able to relate to other people's emotions and feelings better'*. Lawrence: *'I'm more in a place where I want to be than I was before I was ill... I don't think there's anything about my illness that's constraining me...'*

At the other extreme, Jim was *'scraping the bottom of the barrel'* as he was in debt after buying a car, and Francine placed herself as *'probably between halfway and surviving'*, explaining how mental distress and iatrogenic effects of weight gain impacted on her quality of life:

I continue to put weight on ... none of my clothes fit me... [I]t's things that on the face of it seem a bit frivolous... but ... to me they're the things that make quality of life as opposed to survival. So my quality of life comes from I guess my friends, my gerbils [laughs] and the sort of belief that I have a [religious] calling ... [I]t's those that add above the sort of baseline of surviving, but if I was on that baseline I'm not sure how I would keep going.

Clark (2005) argued in the context of South Africa for the importance of incorporating consumer items in capabilities evaluations of quality of life. Francine brings this into the Western context, suggestive of a modern equivalent of Adam Smith's principle of the 'linen shirt' to preserve dignity (Sen, 1999) and highlighting the importance of relative rather than absolute poverty in evaluating wellbeing.

All other participants placed themselves at about halfway between thriving and getting by, these perceptions often contingent on mental distress and related outcomes, including lack of money, iatrogenic effects, or the bathos of memory of a more flourishing pre-distress life, and reinforcing from the first stage interviews the difficulty of thriving with mental distress.

## 8.4 Experiences of thresholds being breached

One of the key principles explicitly for Nussbaum (Wolff and deShalit, 2007, p.40) and implicitly for Burchardt and Vizard (2011) is that just one of the domains being breached is an indicator of a person being in some important sense deprived.

Whilst the subjective and highly interpretative character of responses made it impossible to be definitive across all domains about which thresholds participants felt had been breached, all participants perceived that they had experience of a threshold being breached at some time: a maximum of eight, a minimum of one, including those with current thriving characteristics such as Steve (2) and Lawrence (8). [Table 3](#) is a minimal interpretation of this, with totals in the final column. Two participants were sceptical that people could achieve all domains at once, for example Jon: *‘all human beings might have all these things at different times but ... if you’ve got all them you’d be doing really well’*. This suggests how far some participants were from achieving central and valuable freedoms, and so affirms the domains’ basic value in evaluating how far particular social groups may be from achieving social justice.

	Health	Law	Partic	Being yrself	Avoid death	Laugh	Know	Animals	I,F,S Life	Valued active	Phys security	Comfort standard	Total
Arthur	x			x			x		x			x	5
Becky	x											x	2
Bridget				x									1
Caroline	x		X	x		x	x		x				6
Fiona	x					x			x	X		x	4
Francine	x		X										2
Harry	x				x		x			X			4
Jim			X						x			x	3
Jon	x					x			x			x	4
Kirsty	x						x						2
Lara	x	x	X	x	x								5
Lawrence	x	x	X	x				x	x	X			7
Martin						x			x			x	3
Monica	x	x	X		x		x		x	X		x	8
Robert	x			x	x			X		X	x		6
Steve	x					x							2
Total	13	3	6	6	4	5	5	2	8	5	1	7	

Table 3: participants' perceptions of breached threshold domains

The responses in part reflect the way in which participants chose to speak about the domains: Becky questioned the basis of the domains, so did not engage fully with the process; some chose to speak at greater length about particular



domains. Bridget with multiple admissions to hospital for suicide attempts did not see herself as particularly unhealthy. Most participants spoke of suicidal feelings, interpreted in [Table 3](#) as being breaches of the 'health' domain, for which one of Burchardt and Vizard's sub-examples is achieving the 'highest possible standard of mental health' (2011, p.116).

So although domain thresholds being breached may not provide a definitive measure of social justice, it is indicative of a lack of underpinning of social injustice that all participants, even those with current thriving, perceived that they had experience of a threshold being breached at some time.

## 8.5 The 'anything else' domain

When asked the 'anything else' question, most participants added domains. Predominant amongst these were spirituality/belief (Monica, Francine, Lawrence, Bridget); a relational dimension, linked for some to living well with mental distress (Caroline, Steve, Kirsty); appropriate medication (Lara); and additional protection from employers (Steve). Even if these were implied in the domain headings, or specified in one of the many examples listed within domains by Burchardt and Vizard, they were not intuitively seen as so by participants.

In terms of spirituality and belief, implied in the 'being yourself' domain by Burchardt and Vizard, participants saw a need for a more explicit recognition in the domains of a spiritual dimension to life. Francine noted *'even my strongest atheist friends will talk about the relationship [with] their children ... that 'there's something more than the sum of the parts''*. Lawrence's experience of spirituality when mentally distressed had stayed with him:

...I've probably thought more spiritually since I was ill... [T]he nature of my illness was ... about having certain powers and other people having certain powers... [I]deas ... about God and Jesus and ... having a soul or something is something that maybe I thought more about... I think I understand more about myself and to some extent I have greater insight in, understanding about, life in general. But I don't think my psychiatrist would say that.

Lawrence's experience when distressed had changed his understanding and perception of the world around him beyond the hospital period, an example of Hopper's (2007, p.876) 'transformative power of psychosis', to a degree that

challenges dominant social norms, characteristic of 'being outside', reinforced through Lawrence's sense that his psychiatrist would disagree.

In terms of a missing relational dimension, and resonating with Nussbaum's (2006) concern with human qualities of empathy and caring redacted from the social contract, Kirsty noted that her quality of life was contingent on knowing that others were also not having domains breached:

...I could have all this stuff [domains]. But if I was living in a society where there was just so much like social injustice ... I wouldn't necessarily call that a thriving life ... there's got to be some element of recognising that you're not just an isolated person but that your life impacts other people's and also things about fairness and justice...

Francine critiqued the '*individualistic nature*' of the domains, and Caroline argued the need for a domain (or sub-domain) that encompassed a relational dimension of thriving, related to her mental distress experience:

...knowing that there's other people ... that even if you are alone in this situation that you can ... enter into a new situation and not be alone... [M]aybe [community] but in a really wide sense ... just that humanity of reaching out to another human being...

These participants draw out that the domains risk understating the role of empathetic conscience in social justice, and that, as seen in the stage one interviews, social relations are important to thriving with mental distress.

Lara argued that existing laws meant that participation in psychiatric treatment was able to be overridden, whilst Steve argued that formal compliance with the law as regards employment was not strong enough to enable people with mental distress to thrive. Lara suggested adding '*appropriate medication ... I don't necessarily mean what my psychiatrist would think is appropriate medication I mean what I would need at the time...*' Steve noted:

...knowing you will be protected and treated fairly by your employer ... [in] my own experience I would say it's important ... so that's a slightly different point to the law...

They are driving at the need for people with mental distress to be protected in employment and to have agency in treatment choices beyond what the law

currently allows, in order to convert thriving capabilities into functionings. This reinforces Wolff and deShalit's (2013) position in their debate with Nussbaum over whether functionings or capabilities matter in measuring the achievement of thresholds: having the formal capability to choose treatment options and gain and maintain employment are not enough, the actualised achievement of these matter, Lara reinforcing Plumb's (2012, p.22) argument that the principle of informed choice only exists if people have alternative choices that they are able to pursue.

The experiences from both stages of this study suggest that there are specific additional social security mechanisms, such as those which Lara and Steve propose, that are needed to secure the ability for people with mental distress to live consistently above minimal thresholds, supporting Venkatapuram's (2012, pp.151-153) and Wolff and deShalit's (2007, p.68 n.15) critiques that Nussbaum has too minimalist an understanding of securing domains. However, laws currently reflect dominant social norms related to mental distress (chapter two) into which people become ordered as safe or risky, rational or irrational, capable or incapable and so on, which lead to discrimination and social injustice.

## **8.6 Participants' methodological and ontological critiques of the domains approach**

The ineffability of pinning down the combination of subjective and objective in the domains approach to capabilities was revealed in responses revealing a methodological and ontological critique, hinted at by participants of Wolff and DeShalit (2007, p.107) but not further explored in their analysis. These data therefore extend their finding.

Kirsty used the diagram to consider her achievement of thresholds in a pragmatic way, whilst opening up a critique:

R: ...it's quite helpful because I can kind of go through it as a sort of tick list ... access education ... I'm doing a PhD so enjoying a comfortable standard of living you know I ... have funding ... I've actually got good physical security and treated fairly by the law ... [I]f you lay it out like that ... they're all in place, but maybe that doesn't accord with the kind of subjective sense of ... how your life is. Because when you first asked

me I was ... definitely not thriving but by this criteria then I probably would be? So is there some kind of yes, gap there or maybe there's more to it than this?

I: Sure I'm with you so there might be cognitive gaps i.e. you've got all these but you're still not feeling subjectively that you're thriving...

R: Yeah, yeah, yeah, totally.

Kirsty suggests that even if all domains are objectively satisfied, this may not accord with a subjective feeling of thriving or good quality of life. Francine expanded Kirsty's point:

...if you speak to people that have all those things ... how many of them might ... say ... they don't have the quality of life they are then expected to have... [O]ther people who don't have those things but maybe have other things would say they have a better quality of life ... people with you know long term disabilities.

So, people may have all the domains, but not see themselves as having a good quality of life, and others that might not have all the domains, or indeed may do different things that are not included, may enjoy a good subjective quality of life.

Meanwhile Becky argued that the domains were secondary, not primary, to human thriving:

I just think they're all just by-products ... on the surface like they're important things ... they make you healthy and happy or whatever but I feel like there just has to be a core underneath everything ... spiritual people ... would talk about ... God, I don't call it God, like ... what a child is like, kind of like being connected to a sense of, like freedom and kind of love ... we know that we're going to die ... all of those things [domains] one day are going to go ... you can't rely on them and children don't rely on an outside sense of identity I don't think...

These highlight the domains as a limited tool for explaining differences in values that are consistent with the agency and diversity principle of capabilities. Francine and Becky demonstrate the way in which the domains approach to capabilities is at risk of squeezing what is valued for a thriving life into an individualised model, leaving little room for alternative value systems, highlighted by social perspectives on mental distress (e.g. Plumb, 1994; Beresford, 2012). This fits with Foucauldian critiques of governmentality, a

critique also echoed by Nussbaum in her (2006) challenge to the social contract, but which now becomes ‘re-trapped’ through her domains model due to its following of liberal norms (Wolff and deShalit, 2007, p.45). It is important to note that Becky has characteristics of ‘being outside’, that Francine is in theological training, and that Kirsty is pursuing a doctorate: these critiques of the normative limits of the domains model being informed through these lenses.

## **8.7 Securing domains over time and clustering disadvantages**

Wolff and deShalit (2007, Ch.3) are ‘especially concerned with sub-populations who are involuntarily exposed to exceptional risks’ (2007, p.217) threatening their security of functionings. The macro-level data (Chapter two) would suggest that this includes many people with mental distress.

Participants in the study had a persistent concern about their subjective distress returning; keeping it at bay was fundamental to maintaining their security of functionings. However, as seen in Chapter three, subjective mental distress was usually experienced as predisposed and precipitated by gaps in the achievement of certain domains, such as physical insecurity (e.g. violence and abuse), lack of a comfortable standard of living, an unbalanced engagement in productive and valued activities, and insecure individual, family and social life.

Some participants lacked domain security. Monica explicitly rendered the frustration of this:

...for my own sanity I don't compare where I am now to where I was before. It's like it's just two separate entities and I just keep it like that. Because if I didn't I would grieve for what I didn't have...

Monica had lost eight domain thresholds and there was no sense of possibility of regaining functionings previously attained despite her being only in her early 50s. Robert, a similar age, felt that he had more capabilities now he was not using alcohol, but still lacked six domains, not even feeling strongly about avoiding premature death. Steve, also in his fifties was different, thriving with no currently lost domains. It is as if people with surviving characteristics have been prematurely aged when by the standards of their society they should still

be in the prime of life. The lack of ‘secure functionings’ (Wolff and deShalit, 2007, pp.65-72; 2013, pp.161-165) or ‘capability security’ (Nussbaum, 2011, p.43) are revealed by using the domains approach as a method. The domains approach demonstrates with less reductionism how this social group may become more fully trapped in social injustice than do, for example, Tew’s (2011) focus on the ‘triple whammy’ model or the focus on stigma made by Chamberlin (2006, pp.xi-xiii).

Wolff and deShalit (2007, p.68) argue in hypothetical examples discrete from their empirical data that, for example, the achievement of ‘play’ and other functionings may be contingent on mental health and bodily health, which may in turn be contingent on having secure housing (Living in Physical Security for Burchardt and Vizard, 2011) and offer examples of similar contingencies (2007, pp.138-149) in which according to empirical studies there are ‘causal connections between functionings’ (2007, p.138). This is compatible with literature on social determinants of health and mental health (e.g. Marmot, 2010). Fiona’s story revealed a number of examples of the clustering of disadvantages. The ‘Bedroom Tax’ had reduced her comfortable standard of living domain, and the ease with which she could allow her son and grandson to stay in her second bedroom a couple of times a week which helped her to be healthy and enjoy family life. This reveals two domains undermined by a breach of a third. The premature death of Fiona’s daughter similarly affected her ability to laugh and to be healthy.

Lawrence and Caroline explicitly spoke about the dependence of some domains on good mental health. Caroline argued that this was required in order to enjoy a comfortable standard of living, enjoy individual family and social life, to be understood, participate in society and enjoy recreational activities. Lawrence also felt that mental health ‘*underpins everything else*’:

...enjoying a comfortable standard of living with independence and security, enjoying individual, family and social life, being knowledgeable, able to understand and reason, access to education and have the skills to participate in society and being able to laugh, play and enjoy recreational activities ... they would be four of the most important for me in terms of having a high quality of life and thriving ... [W]hen you’re not well you can’t ... participate in those sort of things...

However, whilst mental health, or the health domain, was perceived by some as a bedrock for securing other domains, as Chapter five showed, emotional hurt expressed as subjective mental distress was predisposed and precipitated by other factors. It requires drawing on the wider literature on the social determinants of mental distress to create a fuller explanation.

## 8.8 Capabilities or functionings?

The stage two interview question '*Is it having the choice to do and be X that matters to you in living a thriving life, or actually doing it?*' (Appendix six) was almost impossible to formulate and ask explicitly. It felt both very awkward and too conceptual. Instead, participants tended to talk in terms of functionings, and sometimes strayed into capabilities, at which point the interview would explore organically what was important in terms of the actual doing or the choice to do. For example, Kirsty talked about the play domain:

I: So ... being able to laugh and play and enjoy recreational activities ... doesn't suggest that you're necessarily doing it or how often.

R: Yes, exactly yes like I've got the capacity just I don't make enough time for it or I don't have enough time for it or yes, yes definitely I'd agree with that.

Kirsty viewed the fulfilment of the domain in terms of functionings, not capabilities - it was a question of her not having enough time for leisure, rather than having the capability but choosing not to exercise it, suggesting an understanding of the domains diagram in terms of the doing, rather than having the sense of agency to do or not do. However, Harry was clear that he could participate in certain groups and activities, but currently chose not to convert this into a functioning, which he did not perceive as a loss, the capability being sufficient. In contrast, Fiona had done HNCs in Social Care and Counselling Skills, having the formal capabilities, but was unable to convert them into functionings due to the impact of her mental distress, a loss to her, the capability not being sufficient: '*... I'm quite pleased that I've got them but I've not been able to use them constructively...*' This complexity reinforces the empirical enigma of capabilities, discussed at length by Wolff and deShalit (2007, chs.3 and 4), but peculiarly they do not relate how their participants discussed this.

Jon described how functionings and capabilities intertwined when contemplating his future:

...the next ten year of my life, I'd like to ... open a fishery. What else? [S]ee that programme ... people ... buy property and they do it up, I'd love to try that... Even if you don't achieve these things but I'll achieve something as long as I'm thinking about these things that are outside my capacity... if I focus on getting my degree, if I focus on five years' time and maybe open a fishery... I may be able to improve my health, I may be able to have money to buy a property ... [I]t might not all happen or it might be different but I think it's better if I have that it's giving me hope...

Whilst this is an individualised description, it gives a sense of how thinking in capability terms, '*things that are outside my capacity*' that may become functionings, and then about what might those functionings lead to in terms of further capabilities, can contribute to planning life activities. Jon expresses a sense of agency in scribing himself a future that encompasses a wide capability set, in the process reinforcing the capabilities critique of utilitarianism, and critiquing the notion that people with mental distress lack hope, which the recovery concept can imply (e.g. Anthony, 1993).

Robert's opportunity to attend college was deprived due to a change in his transport benefits, the functioning reverting to a capability, a loss to him. He would also have liked pets, but worried who would look after them if he became ill. He therefore had at least two capabilities unconverted into functionings, breaching two thresholds. This also reveals how subjective domain achievement can be, reinforcing the inherent diversity of capabilities (Davidson et al, 2009, pp.42-43), suggesting that questions of taste may be one means to resolve this tension.

Questions of taste help to explain whether achievement of domains are best measured as the capability to achieve or the functioning of achievement, and provides a means of explaining the two 'low-weight' domains of play and other species removed by Burchardt and Vizard (2011). On the one hand Harry noted that animals, plants and the world of nature made for a fuller life but were not vital. Thus they were important to his thriving beyond a utilitarian baseline, the social justice space that is a core distinction of the capabilities model. On the other hand, Lawrence noted that animals, plants and the world of nature were



*'just not me'*, a question of taste, a capability that he did not currently wish to convert into a functioning. The question of 'taste' provides an original contribution to the perennial debate about whether functionings or capabilities are the appropriate measure of achievement (e.g. Nussbaum, 2011; Wolff and deShalit, 2013).

However, the data suggests that whilst the question of taste is of salience, there is more complexity to the question of whether capabilities or functionings provide the appropriate measure of threshold achievement, as seen in the analysis of this issue in Chapter seven.

In response to this discussion in the stage two interviews, two participants specifically talked about their experiences of having functionings specifically restricted by the state. Lawrence had passed his driving test and disclosed his mental distress experience to the DVLA, who required a psychiatrist's letter. He only received a 12-month licence, rather than the usual ten years. So, his functioning of driving was temporally constrained by the state due to his mental distress history, demonstrating the power of the clinician and the implications of diagnosis/medication for inhibiting both functionings and capabilities, reducing his ability, for example, to make life plans, and to use a car as a fertile functioning to enable capabilities (cf. Caroline Ch.7).

Jim as a registered sex offender had his family life domain restricted by the state:

R: I cannae make decisions for myself or do anything without their approval. I cannae move, change address without their approval. I have to give them a months' notice.

I: Without whose approval?

R: The Tribunal. I need to give them a month's notice if I'm moving address...

Jim's freedom of movement was monitored, in the interest of protecting others. His functionings were therefore strongly shaped by state with the aim of constraining his capability of harming others. This type of case is not addressed by Wolff and deShalit (2007) or Burchardt and Vizard (2011), but is compatible

with Nussbaum's (2003) theoretical critique of Sen's liberal approach to freedoms: the capabilities approach is normatively based on an assumption of rights to capabilities, but what if doing so restricts or attacks the capabilities or freedoms of others? As seen in Chapter two, Section 2.6 above, survivor-influenced sociological studies also do not always incorporate these empirically-evidenced dilemmas, so further demonstrating the advantages of the normative approach taken by a capabilities analysis. This example demonstrates that in the real world these issues are important to incorporate into social justice analysis; for Jim, his capabilities may include activities which impinge on the capabilities of others. Therefore the normative role of the state is to focus on balancing the competing freedoms of both whilst protecting threshold domains for each.

Jim and Lawrence's examples demonstrate benefits of a capabilities analysis for a fuller understanding the types of choices faced by the state and state actors in considering their normative role. If, as Nussbaum seeks, upholding threshold domains is the responsibility of each state, considering the question of what that upholding means through considering both capabilities and functionings appears to hold potential, requiring further research beyond this thesis.

## **8.9 Experiences and perceptions of the twelve domains**

Using the domains diagram revealed examples of how people had thresholds breached, depriving them of social justice, and showed ways in which breaches impacted across domains, reinforcing Wolff and deShalit's concept of corrosive disadvantages (2007). They raised some new questions about the domains from the original perspective of people with mental distress. This section continues to follow the 'participation' principle for defining domains, addressing the empirical gap identified by Burchardt and Vizard (2011) for people with mental distress, and providing an original contribution to the capabilities debate. Headings in this section constitute the standard and plain English versions of the domain headings on the diagram discussed with participants (Appendix eight). Each sub-section starts with a brief summary of Burchardt and Vizard's (2011) examples of capabilities that for them constituted each domain, sometimes with reflexive commentary on changes made for the purposes of my diagram.

### 8.9.1 Being healthy / Being healthy

Burchardt and Vizard (2011) provide seven examples for this domain, including the ‘highest possible standard of physical and mental health’, and equal access with consent and without stigmatisation, to medical treatment, care and information, whilst maintaining a healthy lifestyle and living in a healthy environment.

This domain drew out contradictions in the notion that health, meaning in this context, subjective mental distress, affected what people could do and be, and about how health could be understood socially rather than medically.

Bridget had experienced mental distress for over thirty years and it was ‘*just another aspect of life*’ in part as she felt well supported by her family, demonstrating how the domains definition of health by Burchardt and Vizard (‘attain the highest possible standard of physical and mental health’ (2011, p.116)) required bringing the social and medical together:

Well it is I suppose, aye mentally ill but it’s just another aspect of life ... I’ve got a lovely family, I’ve got a lovely daughter, son-in-law, grandson and I’ve got more positives. All right I have got this illness but I’m well supported...

Lara similarly argued that her subjective distress was contingent on the support of others:

...I think what matters is that you’ve got the support you need when you’re not healthy ... it’s still not great but it’s better than being on your own with it. But that can be quite hard to find ... proper, real support.

These draw out how participants could define health socially, reinforcing this study’s definition of social justice as the ‘abilities to be and do things that make up a minimally good, flourishing and non-humiliating life’ without necessary reference to formal medical status or category.

Several participants objectively dismissed the suggestion that being healthy was a prerequisite of thriving, whilst subjectively noting that their subjective distress did affect their ability to thrive, including affecting other domains, such

as life, social life, laughter, expression, knowledge and productive activities.

Kirsty noted:

...maybe I've got lower expectations because maybe I think that I'm doing OK if I don't want to kill myself whereas other people ... that would be like way down their kind of perception of what being well is... [T]he kind of mental stuff is always going to be there, and every day it's ... a battle to just keep the wolves from the door...

So, these reinforce the finding from chapter four that mental distress did have a material impact on what people could do and be, and on the interrelation of domains, reinforcing the recent empirical findings of Benbow et al (2014) also in the context of mental distress.

### 8.9.2 Avoiding premature death / Not dying young

Burchardt and Vizard (2011) express this as 'The capability to be alive', the title of which I changed for the purposes of the diagram more radically than that of other domains. Their title does not seem to capture the meaning of their two examples: avoiding premature mortality through disease, neglect, injury or suicide, and protection from being killed.

Participants could provide a particular commentary on this 'life' domain, as most had experienced suicidal feelings or actions. Caroline drew out how hard it can be for a person to conceptualise this capability when they have actively considered ending their life: *'I've never died but I don't know how that comes in when you're feeling suicidal because that's been an issue in the past...'* Francine specified how she had contemplated breaching this domain by ending her life, in what is also more than a simple 'adaptive preference':

...the times when I've been suicidal ... sort of objectively I've known it's irrational but ... for me it was that kind of instinct to survive that all of us understand turned into an instinct to die ... survival was just not an option and for most people most of the time death is not an option ... So my body's screaming out... 'I just want to go to sleep and never wake up' ... but it's the rationality of almost talking to myself and saying, as somebody pointed out once to me 'it's a very permanent solution to a temporary problem'.

So, Caroline and Francine had maintained this domain, but suggest that 'The capability to be alive' (Burchardt and Vizard, 2011) is a very fragile minimum for

people with mental distress, for a domain whose breaching is absolute in a way that does not apply to other domains. Is this what Nussbaum and Burchardt and Vizard really intend? The focus on people with mental distress reveals very clearly how all the other domains are returnable from if breached; this one not so. The data reveal the 'capability to be alive' as a very low threshold of social justice. Looking at this through the eyes of people with mental distress suggests that this domain requires a higher bar to secure social justice.

### **8.9.3 Knowing you will be protected and treated fairly by the law / Being protected and treated fairly by the law**

Burchardt and Vizard (2011) suggest eleven examples for this domain, encompassing equality before the law, protection from intolerance, freedom from arbitrary arrest, fair trial, access to advocacy, freedom of movement, respect for privacy and the right to hold property.

People with mental distress might be seen as an archetypal group whose experience, especially in terms of de facto or compulsory detention in hospital would provide a critique of this domain. In terms of aspects of the law directly related to mental distress, Lawrence's '*biggest concern*' would be '*becoming ill again and ... not being able to get out of the system and I don't know that your rights are protected maybe as well as they should be...*' He also suggested a contradiction with clinical notions that imply objectivity to mental health/illness:

...your right to self-determination is taken away from you because you're not even fit to have it till they determine you are and if you continue to disagree with them you won't get it back, if you play the game you will get it back but that doesn't necessarily reflect the state of your mental health...

On the basis of this experience, Lawrence argued:

...there's still certain ... things you have to say, certain attitudes you have to display, that will convince them that you're well, that if you didn't do that then they might determine that you were unwell... [I've] been in there three times and seen ... a lot of different cases...

Judgment about the need for compulsion seemed to Lawrence not to be solely made on the basis of a transparent and accessible set of procedures or the five

criteria for making a Compulsory Treatment Order in the MHA 2003, but on the presentation of the self. This experience therefore breached self-determination and freedom of speech (the Being Yourself and Participation domains) as well as the Law domain, exemplifying the difficulty of disaggregating the domains, as discussed above.

Lara argued that people with mental distress could experience having the law threshold breached in terms of equality before the law and fair trial, as *'you are not a reliable witness... and if it ever went to court they'd just bring up your mental health problems and you'd be discredited...'* This had personally happened to her:

...something happened and I went to the police and they took it as far as the Procurator Fiscal ... and the Procurator Fiscal basically said that ... with her mental health record that they wouldn't take her as a reliable witness and ... without her testimony it wouldn't stand up enough, so they threw it out.

Caroline had worked as a psychiatric nurse and described an incident in which a person was mistakenly compulsorily detained because their story was not believed:

...it stuck with me that 'what if one day I'm sectioned [laughs] and the police bring me in?'... I just think it's important that, especially regarding stigma and all the other things, that we are protected...

She argued for greater legal protections for people with psychiatric histories because of the additional risks they face due to their discredited social position, comparable to the arguments above for changed legal structures 'over and above the law' to improve agency over medication choices and to improve employers' norms (section 8.5).

So, applying the domains model enabled a critical commentary on the law domain: people with mental distress were not confident that were treated fairly by mental health-specific laws or by wider laws. These reinforce the role of medical and wider social norms in shaping these unequal experiences, and the interdependence of domains is again demonstrated in the negative impacts of these threshold breaches on the achievement of other domains.

### **8.9.4 Participating in decision-making, have a voice and influence / Having a say over things that are important to you**

Participation had six sub-examples for Burchardt and Vizard (2011), including participation in relation to your own life, in groups, and in policy and politics. Given the rights for participation included in the MHA (2003) and the ethic of participation in social care, contrasted with the right to override participation in the best interests of the patient and the prominent history of the struggle for psychiatric patient rights, this domain seemed likely to elicit instructive data.

Lara questioned the validity of the argument made to justify the role of mental health services, that overriding participation and constraining people to hospital are required to avoid premature death:

I think my psychiatrist probably does think that but the hospital environment doesn't help... [I]f I went into hospital and there was somebody who would actually sit and talk to me ... if there was things to do during the day ... it might even just be a little bit more helpful. But ... if you go and tell the staff you're struggling they hand you PRN right, why can't they just give me PRN at home then really...?

She felt that a more participatory approach might be more therapeutically helpful to mental distress, citing the Finnish Open Dialogue Project.<sup>11</sup> This approaches crises differently, emphasising listening and collaboration and starting from a treatment meeting, typically occurring within 24 hours of an initial call to the crisis service and which gathers together everyone connected to the crisis, including the person at the centre, their family and social network.

Monica highlighted the lack of participation in the benefit system, and the resultant stress of this. A friend with multiple health issues had been assessed as ready for work:

[I]t makes me quite anxious about ... decisions that'll be made about me ... next year I'm up for another review with the Benefits Board, and it's very anxiety provoking because there's just no way that I could hold down a job just now.

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<sup>11</sup> See [www.dialogicpractice.net/open-dialogue/about-open-dialogue/](http://www.dialogicpractice.net/open-dialogue/about-open-dialogue/), sourced 01 February 2015.

As she says, '*decisions can be made about you*': lack of participation is the assumed model in the benefit system, in this case stimulating subjective distress.

So, certain areas of life inside and outside the mental health system were not amenable to participation in decision-making. Monica and Lara point to the consequences of this minimisation of agency, including increased anxiety, and less efficacious psychiatric improvement, suggesting that for people with mental distress lack of participation may have corrosive disadvantages (Wolff and deShalit, 2007) leading to breaches of health and other domain thresholds.

### **8.9.5 Being yourself, expressing yourself, and having self-respect / Being yourself, expressing yourself, and having self-respect**

Burchardt and Vizard (2011) included nine examples in this domain, encompassing freedom of conscience, belief and expression, being able to communicate including with ICT assistance, engaging in cultural practices, having self-respect, living without fear and with dignity, and accessing public spaces.

There were several ways in which people had this domain breached. Discussing the concept of being yourself, both Bridget and Caroline referred to their caution in disclosing their mental distress, due to stigmatising attitudes. Caroline explained how this led to a lack of self-respect, as with breaches of the health domain, impacting negatively on the achievement of other domains, another example of corrosive disadvantages (Wolff and deShalit, 2007):

...it feels as though you're living a lie and people aren't getting to know the full you ... so that itself ... feeds into your lack of self-esteem so that then can ... eat into the other boxes such as engaging in valued activities, feeling secure...

Freedom of expression could conflict with feeling suicidal, for example for Lara, having to say the right thing rather than the true thing to statutory services:

The Samaritans, they don't judge what you're saying ... don't get all 'oh we have to do something about this' ... I've had that once from the Samaritans ... I had overdosed and I was falling asleep on the phone so I



think they were justified in saying ‘can we call you an ambulance?’ But ... if I mention suicide to out-of-hours [I] get their standard list of questions, assessing risk and ‘do we need to put you in hospital?’ type questions which then shuts me down because I know exactly what they’re doing...

The Samaritans enabled greater scope for self-expression before intervening to override agency that may risk Lara’s life domain. Lara was aware that agencies with statutory responsibility would intervene at an earlier stage, so she navigated this, comparable to Lawrence in the law domain being aware of the ‘game-playing’ required when needing a favourable decision to unrestrict freedom. For him it would require rhetorical agreement with the psychiatrist, regardless of inner feelings, as Lara had to close off her true feelings in order to remain free.

#### **8.9.6 Being able to laugh, to play, to enjoy recreational activities / Being able to laugh, to play, and to relax**

For Burchardt and Vizard (2009) ‘play’ was recommended for the Equalities Review children’s list, but it did not appear as a central and valuable freedom for adults (2011), ‘laugh’ also playing no role. This contrasted with Nussbaum’s argument (2006) that these are central human capabilities.

The importance of this domain was highlighted by about half the participants, often in poignant relief to times when they had not been able to enact laughter in particular. It was the first domain Steve selected as important to him:

...depression you’ve lost your ability to smile ... that’s a huge loss of the person you are ... actually seeing it written down is very, has a big impact on me.

Whilst people without mental distress might take laughter and recreation for granted, Jon suggested that he had actively learned to appreciate this domain:

...I’ve had to learn to go right into that to help other areas of my life because if you’ve got illness it can be hard to enjoy anything... I took up fishing so that’s helped me in the recreational to try like college...

This reveals a constraint with Burchardt and Vizard’s (2011) method of using a limited range of consultative groups alongside formal human rights instruments

as the basis for developing their domains. Dimensions of human existence that may appear as secondary or unstated to some social groups can be revealed as core to wellbeing for social groups that have had these functionings threatened. This further suggests the advantage of starting from a more philosophical approach to human needs, as with Nussbaum's approach. This also suggests that testing the salience of particular domains with groups that have been deprived them, for example evaluating the salience of animals, plants and the world of nature or enjoying family life domains with long-term prisoners, may be empirically helpful for development of the domains approach to capabilities.

This threshold was revealed as being partly dependent on experience of subjective distress. This suggests that minimising determinants of mental distress would help to maximise the achievement of this domain, alongside the creation of social relations that optimise opportunities for laughter and recreation, an extension perhaps of Wolff and deShalit's proposition for more inclusive social spaces (2007, p.176-177).

#### **8.9.7 Being knowledgeable, able to understand and reason, to access education, and to have the skills to participate in society / Knowing things and being able to get to know things, including at school or college**

Burchardt and Vizard (2011) listed six examples in this domain, encompassing the highest possible standard of knowledge, understanding and reasoning; being intellectually fulfilled; developing skills for participation in valued activities; accessing education and training; and accessing ICT to enable social participation. In my diagram, the word 'education', and 'school or college' for the easy-read version, was added to Burchardt and Vizard's title, in order to make it less conceptual and more tangible. This may have pushed responses to this domain towards formal education.

Arthur, in his forties, had not known that he could access education until informed by a voluntary sector mental health organisation:

R: ...when I first came here a couple of year ago, they told me there were schools and colleges, there were things you can do ... a computer class I went to things like that...

I: So did you know that these things existed though?

R: No I didnae know, no.

He had this aspect of this domain breached, and then enabled by a specialist organisation acting as a positive social Conversion Factor, supporting him to reach the threshold. Robert was attending college: *'college to me was brilliant because I was doing like working with others ... I've done like tons of college courses ... it has a big impact on your life...'*. However, he had this threshold undermined by a funding change - a negative social Conversion Factor - removing his travel pass.

Responses to this domain also impressed how both Nussbaum and Burchardt and Vizard's models may embed inequality, as one person's educational achievement may be far higher than another person's, for whom the threshold has been formally achieved, but with the potential for huge inequalities above the threshold. Lawrence, with thriving qualities, understood the value of having gained a higher education before experiencing mental distress in terms of being able to fulfil his capabilities:

...having secured my education before I became ill I think was pretty critical for me, I think if it had happened like during university... it would have been a lot more difficult to ... achieve what I was capable of achieving...

However, the context of knowledge matters. Lawrence had a First Class Sociology degree but found himself *'pretty ignorant'* of the mental health system. His formal learning in one area did not provide the practical understanding needed in another in which his freedoms were removed.

### **8.9.8 Relating to animals, plants, and the world of nature / Having pets and enjoying the outdoors**

This domain was demoted by Burchardt and Vizard (2011) from Nussbaum's proposed list, as not being highlighted in their consultative process or in human rights instruments.

In relation to animals, in the Stage One interviews, Jack, Jon, Tim and Barbara (*'I don't know what I'd do without my wee dog ... I sit and talk to her, and she*

*knows when I'm down, as well...')* valued the company of pets. Arthur specified the benefit for him of taking responsibility for a friend's dog:

...the dog makes a difference. Looking after something that cannae ... open a can of meat or cannae walk out of a door ... it gives you a great buzz ... Because it can't do it itself so you have to do it ... if I wasnae had the pet I don't know what I would do...

Francine went further, discussing pets' importance in terms of her life and death: *'one of the things that keeps me going is my gerbils because then I think well if I die and no one finds me ... what's going to happen to the gerbils?'*

Harry, discussing the domain as a whole, distinguished between what is vital for life, versus what makes a qualitatively fuller life, a distinction also expressed by Wolff and deShalit's participants (2007, p.51):

... I think it makes a whole, a fuller life, I don't think it's vital but ... I love watching plants grow and my cat ... and ... wee foxes looking at me when I'm digging...

Jon fished and identified the benefits of nature to his mental distress: *'the fishing I see it as God's creation, out in the country it's peace and serenity... when I go to these places it's helping my health...'* He links the outdoors to faith or spirituality which - like this domain - people may not value as a functioning at all times in their life, reinforcing the question of whether the capability, rather than the functioning, should be enough to satisfy the basic human need in instances of questions of taste.

Jon also enjoyed hillwalking, but pointed to the difficulty of affording to travel to the hills, lack of the comfortable living domain (below) impacting on the animals and plants domain. Arthur reiterated the point from his personal experience:

...you have to walk miles to go hill walking if you stay in the scheme that I stay in, there's no hills at the back of me. So I can't go, I need money to go and travel, to go hill walking ... to go ... on a holiday.

This section suggests that for some people with mental distress having pets is central as a functioning, even to the utilitarian point of protection of life, and so core to social justice. But for others it is the capability, not the functioning, that

is sufficient for a thriving life, a question of taste. This respects agency and diversity, but raises difficult questions of comparison and equity. Access to nature adds to thriving for some, but this, at least for urban dwellers, is money-dependent.

### **8.9.9 Enjoying individual, family and social life / Enjoying individual, family and social life**

This domain for Burchardt and Vizard (2011) has sixteen examples, including being able to develop as a person, pursue objectives, have a private life, have peace of mind, form intimate relationships, celebrate special occasions, spend time with and care for others, and enjoy special support when having children. It crosses a range of human qualities from being able to plan a life to having emotional engagement with others. It is thus a portmanteau domain which significantly overlaps with other domains losing a large amount of discriminant validity.

Most data in response to this domain related to the role of family in relation to mental distress. The question of having children was strongly elicited in the stage two interviews, hardly present in the stage one interviews, demonstrating that asking people questions using the domains framework could draw out complementary social justice data. Arthur, Harry and Robert talked about the tension between having children and mental distress. Harry and his partner had not had children as his wife was experiencing mental distress and took Lithium during the period in which they considered this:

R: ...we don't have any children so and that was a choice because of mental health with [wife] because she ... wouldn't have been able to cope with that and certainly the medications that she was on ... she'd have had to come off of them to have children, and that just wasn't open for discussion.

I: Oh right, that's interesting. So the hospital or hospital specialists were of the view that she would have to come off.

R: Yes.

I: Or you yourselves were convinced of that?

R: We were convinced of that, they said the same because the medications they said were toxic to children. And ... she would have to come off them, and if you'd known her at the time ... she was catatonic half the time and that wasn't down to medication that was just down to depression in the true sense of the word where everything's just shut down.

Their agency to have children and be parents was disadvantaged by a combination of subjective mental distress; their understanding that medication did benefit his wife's distress; and their understanding of the contraindication of Lithium with pregnancy, affecting the health of the child.<sup>12</sup> A 'pincer movement' of social Conversion Factors (medication) and personal Conversion Factors (mental distress) combined to constrain this capability, medication acting as a positive Conversion Factor for Harry's wife, but acting as a negative Conversion Factor for their having children.

Arthur's language combined the normative and the subjective, expressing concern that the stress of children might stimulate his and his wife's subjective distress, apprehension about potential removal of children by authorities, and fear that children may be materially upset by his own distress:

...well I'm schizophrenic and she's manic depression Richard, I don't think we should have the responsibility of having a child ... maybe when I wasn't schizophrenic but the now I don't think I could cope ... or she could cope, I think it would put us into screaming and shouting and that'd put us into a bad depression. So ... we know we couldn't have any kids... [W]e've discussed it ... people she [wife] knew was ... schizophrenic and got the children taken off them because they couldn't watch them ... that is what would happen to us...

Arthur's agency to fulfil this element of the family life domain was constrained by his assessment of the potential negative consequences for wellbeing. His assessment had a fatalistic quality, contradicted by Bridget, with multiple diagnoses, 'psychotic' experiences and hospitalisations, who had brought up her daughter (*'I've seen some of my notes and I've read through them ... every single one ... said that I was always a very warm and loving mother...'*), demonstrating that people with mental distress do not have to follow the scenario feared by Arthur. Although this was, as for Harry, a considered choice,

<sup>12</sup> There is some evidence of contraindications, see <http://www.choiceandmedication.org/nsft/medications/72/>, sourced 31 March 2015.

Arthur is living out an agency/wellbeing dilemma, affecting Harry too, leaving them outside the dominant normative expectation that adults can have children.

So agency to have children as part of the family life domain was shaped by dominant social and structural norms translated into empirical realities. Norms that people with mental distress cannot cope with children are made a living reality by, for example, weak social supports for parents with mental distress (Stalker et al, 2011); a continuing medicine-first approach to managing mental distress; few options for alternative management programmes to medication; lack of informed advice about how other families (such as Bridget) have coped with mental distress and parenting; and lack of information about adoption or fostering choices. These all act as negative social Conversion Factors and reflect, adapting Sennett and Cobb (1972), one of the ‘hidden injuries’ of mental distress.

Martin also had no children, and said that his family relations *‘could be better’*, *‘a lot of them have died’*. If people with mental distress are more likely to live alone (Mind, 2004) is it possible that their thriving in later life is disproportionately affected by deaths of peers, parents and siblings, making this domain particularly salient to this social group? In line with this, Bridget highlighted the importance of her family in terms of literally calculating the value of life, comparable to the role pets played for Francine:

...you weigh it up and you say to yourself what positives is there and what negatives is there? Positives ... I’ve got a lovely family, I’ve got a lovely daughter, son-in-law, grandson... I have got this illness but I’m well supported, I’m very lucky ... the only other thing you can do if you can’t be positive is end it...

Jon brought the three dimensions of this domain together by looking back to the way in which not having experienced a good set of family and social capabilities as a child affected his social justice:

...I’ve got to live with the consequences of how other people, family have lived their life and how I’ve got to not get bitter and resentful for being brought up with one parent ... [F]or me it’s harder to achieve where I’m going because of my lot.

These data uncover a gap in capabilities literature about how failure to achieve this threshold is judged, in terms of temporality. Jon has had this threshold breached in the past, which has consequences for his thriving now. The temporal dimension of the threshold of this domain being breached, for example in terms of the evidence of childhood abuse and its potential impact as a determinant of mental distress (Office of the Deputy Prime Minister, 2004) makes this domain of particular salience in terms of its consequences for a thriving life. The concepts of family and social life imply social determinants and social gradients, but the capabilities approach's limited integration of these wider explanatory factors (see e.g. Venkatapuram's critique of Nussbaum, 2011, pp. 150-153) are revealed through analysis of Jon's experience using the domains model.

So, asking people with mental distress about this domain drew out that family life could provide a reason to live, but also of breaches of the norm of having children. It also reinforced earlier data in chapter seven about family and social determinants predisposing or precipitating mental distress with consequences for how domain threshold breaches are evaluated.

#### **8.9.10 Engaging in productive and valued activities / Doing useful things**

Burchardt and Vizard (2011) use eight examples to encompass work with support where necessary, caring, unpaid work, leisure, an equal right to balance these, and free choice of occupation. In my diagram, leisure was included with laughter and play, which felt more intuitive and followed Nussbaum's original domains.

Participants made points about this domain's definition, normativity and philosophical foundations, and about the tension between paid and unpaid work. Kirsty linked a critique of the participation domain to productive and valued activities, reinforcing capabilities' avoidance of capitalist social relations, highlighted in chapter three (e.g. Harvey, 2014):

...participate in society, what does that mean? Like does that mean be a productive member of society and contribute to the capitalist economy?  
 ... [E]ngaging in productive and valued activities ... you could read that in different ways but yes what's productive? What's valued? By who? Who gets to decide?



Steve valued caring activities (also emphasised by Wolff and DeShalit, 2007, pp.45-46; 58), his opinion informed through feeling worthless in hospital:

... productive and valued activities ... you get into all sorts of definitional issues about valued for what and by whom ... for me it's about ... self-worth because ... when I was in hospital I felt worthless... so that value might be ... activities that you feel good about yourself for doing, rather than being valuable from a financial sense... [T]ime spent with people you love... Helping other people that you love...

So, participants asked questions from their experience about what is productive and valued and who does the valuing. Whilst Burchardt and Vizard (2011) included unpaid work and caring in their examples, they treat these as if they are of equivalent social value to paid work when they are not. Sayer (2012, p.3) notes the tendency of capabilities analyses to overlook how opportunities to expand capability sets are shaped:

...how labour markets and an unequal division of labour create structural inequalities that restrict the capabilities of many workers, frustrating efforts to improve well-being via approaches that target personal, internal capabilities.

Burchardt and Vizard's analysis is a case in point of overlooking how these opportunities are socially determined, sociology thus critiquing the undertheorised capabilities notion of socially valued activities (Hopper, 2007, p.874).

This played out another way for Robert and Lara. Robert felt that doing useful things was *'very important'*, useful things to him being *'helping [name of Children's Hospital] ... for me that's useful... It gives you a purpose in life ... you're helping ... kids that's dying with cancer...'* His doctors were happy that he was doing voluntary work; paid work would potentially jeopardise his supported accommodation due to the benefits trap, in turn threatening his living in physical security and comfortable standard of living domains. A tension is revealed: the dominant social norm of paid work may jeopardise other domains. This suggests that the benefit system is paying for Robert's literal social security, and that the dominant norm of productive activity as employment may create a threat to other capabilities due to the inflexibility of the same benefit

system, reinforcing Wolff and DeShalit's (2007, p.70) notion of cross-category risk.

Lara reinforced the contradiction between pursuing personally meaningful non-employment activity, and the contradiction with the benefit system:

I love that one, engaging in productive and valued activities, because it doesn't define them ... I do some volunteering, I've done different things ... that I find really valuable ... I have a slight issue with the changes to the benefit system because, say I'd been put in the work group and they decided they wanted me to do say a work programme and I was volunteering somewhere that I found valuable and meaningful for me I would be told to stop that volunteering and do what they wanted me to do ... I'd love to go out and get a job tomorrow if it was realistic, but up until [then] I want to do something that for me has meaning.

What changes to the 'external conditions of capabilities' (Sayer, 2012, p.3) or 'the systemic impediments to human freedom that are associated with the capitalist mode of production' (Dean, 2009, pp.271-2) would be required for these types of personally valued activities to become socially valued, thus being part of social justice, and how might the social security system best support this? The question that the domains model aids thinking about is how dominant norms can pay more respect to peoples' agency and freedom to do personally valued activities that may - or may not - have employment and 'getting back to work' as an ultimate aim. This reinforces the findings of chapter seven on employment and equilibrium, the induced and deduced data begging the same questions.

### **8.9.11 Living in physical security / Being safe**

Burchardt and Vizard (2011) provide four examples, in summary being free to use public spaces and being free from violence, abuse and degrading treatment. Whilst these might be thought to resonate with the oppressions faced by people with mental distress through social stigma and enforced psychiatric treatment, this domain had fewest responses, in part due to the 'discriminant validity' problem for the domains and the clockwise tendency of use of the diagrams (Appendix eight), these types of issue having been talked about earlier, under for example the law, self-respect and participation domains. This domain was interpreted quite narrowly as being about the home, hostels and hospitals.

Harry and Monica emphasised how safe they felt at home. Harry lived in an area with an unsafe reputation, but felt:

...free from threat, harassment ... the front and back door aren't locked during the day... It's like a big village, everybody knows everybody what's going on so it's an informal neighbourhood watch...

He reveals that he was not threatened or stigmatised, critiquing social perspective assumptions and demonstrating the advantage of using the domains model to explore social justice concepts across a broad demographic of people with mental distress as this study does. Steve also felt safe in his neighbourhood, but his experience in hospital gave him a taste of the lives of others:

...living in physical security I mean I am probably fortunate in that respect but ... people I'm thinking of in hospital maybe living in hostels at times ... for them that could be a really crucial issue ... I never understood the word asylum until I was in the psychiatric hospital ... it was a place of physical safety and security ... [P]eople would tell me stories of being in drug rehabilitation hostels ... where physical security wasn't possible ... I was actually surprised at how safe I felt but it wasn't a hundred percent guaranteed for all patients at all times...

The insecurity of hostel life was confirmed by Robert, who had lived in several and was currently in supported accommodation.

... support's very important especially if you've had ... issues in your life ... Being Safe, that to me is very important... I mean basically you're not going to get hassle as long as you've got support from the staff ... there's guys in hostels they get all sorts of hassle ... I had that before...

Living in physical security was very important to Robert, and considering this domain helped him to specify why.

#### **8.9.12      Enjoying a comfortable standard of living, with independence and security / Having a comfortable and secure life**

Burchardt and Vizard (2011) provide eight examples, summarised as having an adequate and secure standard of living, including independence and dignity and with care and support where needed; being able to travel; having control over where and how to live and how to spend our money; security of housing, access to the natural world and to 'share in the benefits of scientific progress' including

medicine and I.T. Again discriminant validity is problematic, with considerable overlaps with other domains, perversely so in the case of the natural world. The dominant normative assumption that scientific progress is beneficial, notably medicine, was critiqued by participants in chapter five.

This domain elicited data about income and quality of life, and engendered dissent about the concept of independence.

Steve's income security was maintained when in hospital, and he could contrast this with the experiences of others:

...a lot of people in hospital with me had money issues and because they were ill they weren't maybe working or their employer wasn't giving them the same money... I was on the same salary throughout ... a lot of people had financial problems that just cascaded the depression if you like further... I was hugely, hugely fortunate...

Steve wasn't simply '*fortunate*'; his life was structured to shape this thriving outcome. Arthur, Fiona, Monica and Martin reinforced concerns about financial insecurity. Monica reflected on her past:

...my life is quite rich but if I compare it to what it was like when I was working it's totally different because I don't have the same financial income so you can't afford to go to the theatre ... the pictures, you've got to cut your cloth...

Thinking about a comfortable standard of living drew out how Monica's capabilities and functionings had been reduced. Arthur and Fiona's threshold achievement of this domain was experienced as easily jeopardised by benefit changes, Arthur highlighting a potential 'trade off' between the health and comfortable standard of living domains if his benefits were cut:

R: ...if the government ... takes my DLA away say, and take my sick money away say, what can I do? Well I can't live on I don't know, fifty pounds a week ... It would be like forcing me to ... get a job Richard, so I would see my psychiatrist and say 'look I have to get a job because the money's not happening, all my life has ended up away down the drain and I want to get back up'... I'm not well but ... I have to do something.

I: Even if that might put your health at risk?

R: Even if that might put my health at risk Richard, aye.

Benefit changes had decreased Fiona's ability to thrive, and again jeopardised her health domain, as having her son to stay benefitted her mental health, at a cost of £7 a month:

...the Bedroom Tax this is concerning me. I have to give out my benefits seven pounds a month so I'm basically paying for my son and my grandson to live in his own house ... I tried to see if ... they would see reason that I needed the rooms for my son and my grandson to stay and I was knocked back... [M]y son can be up twice a week and staying overnight... because of my mental health problems I need a room for him.

The domains approach draws out that income could contradict the being healthy and family life domains, again revealing domain interdependencies.

The concept of independence in this domain was questioned by Monica and Francine. Monica did not agree with this aspect, having supported her sister when she was physically unwell:

I don't think it's about independence it's about interdependence. There are times when my sister wasn't well and I was there to support her and there's times now that she's well and she supports me...

Francine's critique of independence was based on her experience of interdependence in the military:

I don't think there's anything necessarily negative about being part of a community or a society ... in the military ... I lived in an environment where ... our lives could depend on the actions of everybody else if there was a fire or flood and stuff. So I wasn't independent ... but I was still valued within that environment ... I think it's more about being valued for what you bring ... if you were entirely independent I'm sure it would be a very boring and isolating life.

These reveal a way in which Burchardt and Vizard's (2011) domains conflict with what Nussbaum terms an 'instinctive' notion of a good life, Nussbaum (2006, pp.76-78) not including independence, but including affiliation, 'being able to live with and towards others'.

## 8.10 Chapter discussion and conclusion

The first three data chapters induced in a relatively open, Senian manner how it feels to experience mental distress and how this, the mental health system and living in society shape the social justice of people with mental distress. This chapter has used the starting point of Nussbaumian domains to explore whether domain thresholds were breached and therefore social justice undermined for the sample, so using a more structured approach to capabilities analysis.

Having undertaken this exercise, Wolff and deShalit's (2007) presentation of empirical findings is understandable - briefly presented and with much interpretation.

The chapter has highlighted the need to consult widely on domains in order to properly represent the lives of diverse groups experiencing social injustice. It found that all participants, even those with thriving characteristics had experienced thresholds being breached, sometimes across multiple domains. If the lack of any domain is an indicator of social injustice it is clear that people with mental distress are not being protected. This reinforces the macro-level data (chapter two) and the findings from the first three data chapters, demonstrating a benefit of this mixed method approach.

The data complemented the analysis in Chapter seven by exploring what breaching thresholds means in terms of capabilities or functionings, extending the ongoing debate within capabilities found, for example, in Wolff and deShalit's (2013) rejoinder to Nussbaum (2011). It found that taste provides one means of evaluating this question, notably for 'low weight' domains of play and other species. It reinforced the complex intertwining over time of the subjective relevance of capabilities or functionings, suggesting that more in-depth qualitative research of this question is required with this and other population groups. And it demonstrated how the capabilities or functionings has implications for the state and state actors in how they underpin domain thresholds for different humans, providing empirical evidence to support Nussbaum's (2003) critique of Sen's more liberal approach.

The chapter also found that two of Nussbaum's domains removed from Burchardt and Vizard's (2011) framework (Play and Other species) did have salience for participants, and that therefore Burchardt and Vizard were hasty in their removal of less formally recognised domains from their model. It also found that participants added domains to those listed, supporting Nussbaum's principle of participation in developing the domains.

Whilst Burchardt and Vizard's consulted domains had salience for participants, they made some critiques, including of independence and the domains' individualised and subjective approach. They identified that interpreting social justice using the domains can be compatible with social determinants of mental distress, and clustering of disadvantages, including in relation to health, were identified, following Wolff and deShalit's sensibility towards 'high weight' functionings (2007, p.122).

### **8.10.1 Using the domains approach as a method**

Participants found the domains method intuitive and their engagement in the process suggested that it was stimulating. The way in which participants could easily identify breaches of threshold demonstrated the benefit of using the domains approach to gain a basic understanding of social justice. However, the conceptual limitations of the domains approach, for example some of Burchardt and Vizard's (2011) domains were seen to be very capacious and others highly focused, and a discriminant validity problem was identified, added to participants' critiques of and additions to the domains, and the challenges of relativism, adaptive preferences and over-subjectivity, collectively demonstrate the risks of oversimplistic application of the domains model, for example for quality of life measures. The method used mirrored that of Wolff and deShalit (2007, Ch.2), and the analysis extends their findings to an objectively disadvantaged group not included in their sample, whilst furthering their analytical critique of the domains approach.

### **8.10.2 Findings – domains**

What participants had to say directly in response to individual domains was revealing in a number of ways. The low salience of physical security

contradicted macro-level data on experiences of stigma. Being healthy reinforced, with critique, the data from chapter five. Relating to animals and being able to laugh emerged as surprisingly important for some. The need for a liberal interpretation of productive and valued activities was highlighted by some participants. Having children emerged as a breach of the family life domain.

Domains such as laughter, play, animals, and being outdoors may be valuable in identifying differences that make for a thriving life as opposed to a utilitarian or rights-based analysis, a core capabilities distinction. Further research should explore whether laughter may be an especially salient functioning for those with experience of 'depression'.

It was striking that the full constellation of the domains resonated with participants, but for some the domains risked missing issues of interdependence, spirituality, connection, moral concern for the unknown other, and a deeper essence to human life. Lack of social justice for others could negatively influence a sense of thriving, demonstrating a need for a stronger relational element, including a care ethic as suggested by Wolff and deShalit (2007, p.45).

This empirical process has also revealed a need for a 'new normative' from the perspective of people with mental distress - how the world should be to support people with mental distress to uphold their domains and therefore the basis of their social justice: better legal protection at work; more participation and agency in psychiatric treatment; and meaningful and valued activities beyond employment that fulfil equilibrium and enable the personally valued to also be socially valued including through security of income. To these could be added better legal and practical support for people with mental distress to have children and be supported, where required, to bring them up.

### **8.10.3 Findings – conceptual critiques of the domains approach**

The data drew out several conceptual critiques of the domains model.

First, capabilities versus functionings. Being able to play, laugh, enjoy other species and bring up children are important as they can typify a difference



between a 'bare' and a full life. However, being with animals and having children in particular are ultimately questions of taste. The capability to achieve these, rather than the functioning, is therefore the appropriate measure for low-weight domains in particular.

Second, integration of the capabilities concepts of agency and diversity. Nussbaum (2003) is right, what is important for people to gain social justice can never be entirely relative or subjective. However, this analysis suggests that future domains-based studies should more deeply integrate agency and diversity.

Third, participants highlighted the risk of domains-based evaluation being individualistic, some demonstrating a wider 'social morality' that was part of their thriving, and for which the domains do not easily account.

Fourth, further work beyond this study is also required to discover the cut-off point at which the loss of functionings within a domain constitutes a threshold being breached. Currently this is unhelpfully ambiguous if domains are to be operationalisable as a means to 'provide a minimal account of social justice' (Riddle, 2014, p.41, ch.4). The analysis has found that beyond the low-weight domains, both capabilities and functionings require consideration in a capabilities evaluation of threshold achievement in order to reflect complexity, subjectivity and temporal significance. Alongside this, there is a need for states to balance the threshold achievements of different citizens or groups of citizens. This requires further research in order to pinpoint the implications of this for Nussbaum's 'minimal account of social justice' (2006, p. 71).

Finally, how far are thresholds about thriving or about minimum dignity, and normatively how much should they be about one or the other in order to promote and secure social justice for this group? This persistent capabilities ambiguity (e.g. Riddle, 2010; Venkatapuram, 2011) was raised here too.

Whilst the domains have provided an operationalisable deductive framework to explore questions of social justice, the induced findings of the earlier chapters, the context of the literature reviews, and the bringing in of structural features related to dominant social norms help to achieve a fuller and more critical

analysis. The concluding chapter of the thesis brings these together, critiquing the sociology of mental distress and capabilities using critical realism.

## 9 Discussion and conclusion

### 9.1 Introduction

The normative aim of social sciences should be to improve flourishing and reduce suffering (Sayer, 2009), an aim that is integral to the capabilities approach as it seeks to promote social justice and reduce human suffering (Sen, 2010). This shared ethical stance has underpinned this study of people with mental distress, a social group persistently understood as experiencing social injustice across multiple domains, as seen in Chapter two.

The research problem that this study has sought to address is whether the capabilities approach can be applied to provide a normative means of understanding the social justice experiences of people with mental distress. It has explored this through analysis of the lived experiences of a sample of people living in Glasgow with recent in-patient experience of psychiatric hospital. The study specifically aimed: to understand the relationship between personal, social and structural factors affecting the lived experiences of the sample; to consider the character of social justice experienced by participants and to conceptualise this using concepts from the capabilities approach; to take a critical realist approach to understanding how the social justice experiences of participants may be produced and reproduced; and to pursue these aims with regard to both values-based research principles from the survivor-influenced literature and the participation principle from the capabilities approach.

The study has provided a structured qualitative explanation, using concepts from the capabilities approach, of how social justice outcomes for people with mental distress happen. Paraphrasing Beresford (2010, p.57), it has reconceptualised mental distress within a social framework. The study has seen the bulk of social justice experiences as characteristic of surviving, a minority of experiences as characteristic of thriving, and some experiences characteristic of 'being outside', the three characteristics able to be embodied within the same individuals in different domains of experience. This provides a nuanced addition to survivor-influenced social perspectives about the meaning of being a 'survivor', explored further below.

By recruiting people with experience of psychiatric hospital, the study listened to people for whom survivor-influenced social perspectives have a particular normative concern (Chapter two). This recruitment criterion also acted as a cipher for a certain significance of mental distress experience, so averting critiques of the analysis being of those with 'minor' experiences. Participants talked about a wide range of social justice experiences, both inside and beyond the mental health sector, these data demonstrating the advantage of taking a 'whole life' approach, rather than focusing more narrowly on service usage. Leaving it up to participants to describe what they actually did and how they actually spent their time opened up dimensions of subjective significance, so reducing the objectification that has been a tendency of research with this social group (Rogers and Pilgrim, 2010). Yet this decision has also contextualised the role of the psychiatric system in social justice outcomes, critiquing the focus of survivor-influenced studies on this singular dimension of experience.

The data has shown how people with mental distress experience the wider social structure, and has demonstrated that experience of subjective mental distress can explain only a part of their social justice status. To conclude from this study's definition of social justice (from Venkatapuram, 2011, p.20): some people with mental distress have very limited opportunity to live in social relations that offer socially valued, flourishing and non-humiliating lives in the contemporary Western world. The data has reinforced Venkatapuram's critique of Nussbaum's account of social justice as missing contemporary evidence on causality and social determinants of health (2011, pp.150-153).

This sociological study could be seen as exploring mental distress using the capabilities approach, or as an interrogation of the capabilities approach using the experiences of people with mental distress. In fact it has allowed an unpacking of both these, allowing the study to make a series of original contributions.

First, capabilities uses a set of concepts in interpreting its ethical values, which this study has demonstrated can be operationalised and interpreted in a small-scale study, far from the methodological origins of the approach using large scale survey data (e.g. Sen, 1987, Appendix A).

Second, the study has gained an understanding of how the ability of people with mental distress to achieve social justice is constrained or enabled by the interactions of personal, social and structural Conversion Factors, an originally adapted version of the personal, social and environmental Conversion Factors, the analytical power of capabilities being enhanced through sociological theory. Personal Conversion Factors included subjective mental distress; social Conversion Factors included social institutions such as the mental health system and the family; structural Conversion Factors included dominant social norms.

Third, the study has shown how applying an originally adapted version of Nussbaum's domains model in an in-depth qualitative study with a particular social group can both reveal domains of salience to that group in the achievement of social justice, and critique the domains approach to evaluating social justice, revealing epistemological and ontological constraints. In the process it has developed the empirical work of both Wolff and deShalit (2007) and Burchardt and Vizard (2011).

Fourth, by critically interpreting the empirical data using a combination of capabilities concepts, in particular Conversion Factors, and sociological concepts, the analysis was able to combine what had been two separate fields of study (Holmwood, 2013) and provide an original interpretation of how social justice is experienced by people with mental distress.

Fifth, the critical realist underpinning of the study enabled the interpretation of participants' perceptions and experiences using weak social constructivism to allow for interpretation beyond the discourses used, whilst also encompassing the integration of concepts from the capabilities approach strengthened through the application of sociology. This meant that agency and diversity could be respected, enabling an 'openness' to the analysis, whilst minimising the risks of theoretical overshadowing or of tautologous conclusions, and allowing normative conclusions to be drawn.

Following a discussion of the substantive findings of each data chapter, methodological and theoretical findings are explained, and then a critical realist analysis attempted, tentatively outlining what is termed a critical capabilities model of mental distress. These are followed by a reflection on the limits of the

study, a normative-empirical description of how the findings can be taken forward, and a short conclusion.

## **9.2 Substantive findings from the empirical data**

### **9.2.1 Chapter five**

The sociology of mental distress has lengthy debate about the relationship between the materiality and the social construction of mental distress. Using the capabilities approach allowed Chapter five ‘living with mental distress’ to conceptualise subjective mental distress as a personal Conversion Factor. It presented what participants said about perceived predispositions and precipitants of mental distress, how mental distress literally felt to them, including suicidal feelings and the mitigation of these, and how together these influenced their agency, what they were able to do and be, and so their social justice. Whilst participants experienced mental distress as being subjectively material emotions, not an externally imposed label or social construction, this did not mean that they interpreted their experiences as simply medical or biochemical. Mental distress was commonly experienced as predisposed or precipitated by gaps in the achievement of other dimensions of social justice, or in Nussbaumian terms, threshold capabilities, such as lack of physical security (e.g. violence and abuse), lack of a comfortable standard of living, an unbalanced engagement in productive and valued activities, or an insecure individual, family and social life. This reinforced both capabilities literature on the significance of threshold domain achievement to social justice (Nussbaum, 2006; Wolff and deShalit, 2007) and sociological literature on the social determinants of mental distress. Capabilities was therefore applied to provide an original way of conceptualising both subjective mental distress and determinants of mental distress.

The data also demonstrated the heterogeneity of distress experiences, reinforcing critiques of categorical clinical diagnosis (Chapter two). Mental distress was generally experienced as problematic, was occasionally valued, but either experience disrupted agency, reinforcing Tew (2011). When positive, it could enable insights that participants could not previously achieve, sometimes breaching dominant social norms. More often mental distress negatively

impacted on what people could do and be. So mental distress, as part of an individual's personal Conversion Factors, yet socially determined, acted to constrain participants' agency, functionings and capability set.

The data on suicide and the mitigation of suicide demonstrated the interplay between personal and social Conversion Factors. These worked together helping to explain how peoples' agency is structured as they navigate the predicament of suicidal feelings, resulting in either an extended life with the non-determined potential for an expanded capability set, thriving and social justice, or an extended, surviving, life, potentially continuing with the predicament, and therefore with the capability threshold for 'life' in continued jeopardy, a social injustice. As 'the ultimate constraint is death' (Venkatapuram, 2011, p.234) this section was able to offer a number of original critiques of capabilities as a result of its exploration of the delicate issue of suicide, which has been underplayed in theoretical and qualitative empirical capabilities literature.

A final key finding of this Chapter was that sociology that seeks to respect lived experience cannot ignore the subjective experience of mental distress. It further showed that when mental distress is described in this detail, it becomes epistemologically impossible to both respect lived experience (Tew et al, 2006) and to generalise about 'people with mental distress' as a social group. Whilst the data showed that subjective experiences did not simply reflect psychiatric or medical categories, demonstrating participants' autonomy from medical discourses, subjective experience of mental distress did not in itself fully explain whether people would have thriving, surviving or being outside characteristics; this required the integration of further data.

### **9.2.2 Chapter six**

Chapter six 'living with the mental health system' explored how the statutory mental health system, including the law, professionals, diagnosis and medication acted as social Conversion Factors, shaped by structural Conversion Factors to influence social justice outcomes. The data demonstrated ways in which the mental health system is organised, including through the law, to contain human freedoms and shape mental distress as being a diagnosable and treatable medical condition. It showed that whilst the system could save lives, crucially

maintaining Nussbaum's life domain, it struggled to influence wider notions of social justice.

Prior to hospital admission participants had a variety of experiences of mental distress and of mental health services, their agency, implicitly or explicitly shaped by the social Conversion Factor of the MHA 2003, in the context of a life in which they were previously achieving greater or lesser social justice. In hospital, participants then entered a specific social structure alongside other citizens and professionals. This could be an unpleasant, even threatening, environment with little significant agency to exit. The short-term role of professionals in hospital included saving life, upholding the most fundamental and yet under-interrogated functioning in the literature on capabilities, revealed by exploring this social group. But professionals could also neglect the wellbeing of participants in hospital, so dignity and justice could be detrimented.

Being compulsorily detained could paradoxically lead to a greater perception of freedom amongst participants, but this was a formal as opposed to substantive freedom, with limits set by the mental health system. However, people could in retrospect agree with the reasons for their detention, suggesting how these formal rights and constraints may expand freedoms in the longer-term, fundamentally to uphold life. By studying this particular social group, therefore, questions about temporal issues in capabilities (e.g. Wolff and DeShalit, 2007) and about the tension between liberal notions of freedom and paternalistic notions of freedom stemming from the originating approaches of Sen and of Nussbaum, were reinforced.

In sociological terms this Chapter demonstrated how the structures of power that shape social order influence social justice for people with mental distress through regulation and containment, embodied in mental health laws and practices. It drew out that these dynamics are complex, the agentic, social and structural working in tension, the highly socially ordered context of hospitalisation, professionals, diagnosis and medication not entirely removing agency. It showed how people become positioned towards surviving, thriving and being outside. Being discharged from this constrained social structure could lead to 'enhanced capabilities' or 'continuing functionings'. Continuing functionings



would mean discharge into the same determinants of mental distress, maintaining social injustice, and so surviving.

In terms of the meaning of diagnosis for social justice, some participants were content to accept diagnoses on the basis of their being resonant with their subjective experience of distress, so providing an explanatory role and helping with managing distress feelings. At best diagnosis was shown to be capable of forming part of a process of regaining agency over mental distress, enabling potential for expanding capabilities. Whilst participants often contested the specificity of the label (i.e. social construction within the general category of mental distress) they did not query the principle of diagnosis, reinforcing dominant medical norms.

Considering diagnosis therefore highlights discourses about the power of the state over the citizen, and non-conscious conformity to dominant norms (Foucault, 1967). This structural layer of analysis is underexplored in capabilities. Nussbaum's (2006; 2009) work on cognitive impairment does not consider the challenges that labelling may afford to equal social respect; whilst embracing social determinants of health, Venkatapuram (2011) does not consider the historical power of the medical model in health or mental health, and Sen takes a benevolent view of liberal society and the state (Harvey, 2014). The experiences of people with mental distress in terms of diagnosis form a paradigmatic case to reveal weaknesses in capabilities' normative assumptions and depth of analysis. The data asks questions of whether, without the addition of sociological theory, capabilities is able to provide a sufficiently critical account of how the 'abilities to be and do things that make up a minimally good, flourishing and non-humiliating life for a human being in the contemporary world' (Venkatapuram, 2011, p.20), are shaped.

Almost all participants recounted both good and bad experiences of psychiatric medication in shaping what they were able to do and be. Participants' lived experiences of medication, including iatrogenic effects, and their impact on social justice showed how medication could support participants to do and be more, but not without costs; how capabilities could be lost when taking medication; how medication could be unpredictable; and how people used their agency to challenge or subvert prescriptions. Medication rarely resolved

subjective mental distress on its own; indeed sometimes it could stimulate it. It could offer a platform for people to be able to do and be different things, potentially expanding their functionings and capabilities. But the mixed and distorting impacts of medication and iatrogenic effects problematised the dominant biomedical norm that medication is a necessary base for expanding functionings and capabilities, reinforcing the survivor-influenced literature (Chapter two).

The complex medication experiences of participants begged the question of why people remain faithful to medication. This is partly explained by the materiality of negative mental distress, including suicidal feelings, but also by the norms of social relations with clinicians, the dominant discourse of diagnosis, and social norms of behaviour linked with wider dominant social norms of health and illness. These start to offer an explanatory logic.

These experiences open a window into a domain of life in which power is very explicit. They can be interpreted in capabilities terms as personal, social and structural Conversion Factors working together and tending to act against social justice for some, with surviving characteristics, and to reinforce the social position of others with thriving characteristics, revealing traces of 'being outside' characteristics, notably in terms of questioning the dominant norms of the medical model.

### **9.2.3 Chapter seven**

In Chapter seven, 'living in society with experience of mental distress' all participants, regardless of whether they tended towards characteristics of surviving, thriving or being outside, had done activities and structured their time in ways that for them would minimise another onset of mental distress, reinforcing its generally negative materiality. Sometimes mental distress or iatrogenic effects could constrain participants' agency to create routine or structure. Sometimes agency was strongly contextualised by the normative values of mental health and other professionals, operationalising medical norms and dominant social normativity, so reducing autonomy in what activities could be pursued. The use of power in this way contradicts the capabilities principle of diversity, and draws attention to Foucault's social order critique of modernity

and the impact of dominant social norms on human freedom (Harvey, 2014, ch.14). The chapter also demonstrated limits to Sen's notion of adaptive preferences as being overly binary and lacking relationality, suggesting a need for further research. It also contributed to the debate about whether functionings or capabilities are important to a capabilities evaluation of social justice, suggesting that whilst there was an affirmatory benefit for the sample in enacting a functioning, as this materially demonstrated what a capability can only offer in theory, capability sets were essential to bring into the analysis, as these provided a context for evaluating the functioning. This demonstrated the added value of capabilities for analysis of social justice both in theory and in practice.

The Chapter found that mental health organisations, acting as social Conversion Factors can contribute to maintaining threshold capabilities, as the mental health system could preserve the life domain. But just as the mental health system had little influence over wider characteristics of social justice, mental health organisations struggled to act as sufficiently positive social Conversion Factors to enable the development of mainstream capability sets, so participants continued to live with capability deprivation and so lacked social justice. Participants separated into two groups, one with surviving characteristics, using mental health voluntary organisations and in a 'predicament' (Barham and Hayward, 1991) or 'trap' (Estroff, 1981), and a second group with thriving characteristics that remained connected to mainstream, socially valued groups and activities.

Chapter seven also described how family and intimate relations, and prejudice and discrimination acted as social Conversion Factors for participants, exploring their impact on their mental distress and agency, and thus on what participants were able to do and be, or their social justice. Characteristics of surviving, thriving and being outside were influenced by these social relations, encompassed by social structures reproducing categories of power. Amongst many findings, reinforcing Goffman (1990), participants were also seen to internalise assumptions of stigma towards people with mental distress, with a singular experience having a high salience. Discrimination and prejudice were specified, and the evidence was that these could be experienced in response to the expression of mental distress being outside dominant social norms of

behaviour, adding complexity to understanding. Participants with thriving characteristics demonstrated the strategic work required to disclose mental distress 'positively' in the context of employment, and so to comply with a recovery 'ideal'.

On an interpersonal level the data showed that disclosure to peers could be positive, and could deepen social relations. However in relation to employment, experience of mental distress meant that participants with surviving characteristics left their jobs when subjective distress contradicted both norms of behaviour and personal capability at work. Those unable to meet the recovery ideal lived 'outside' socially valued mainstream employment and reverted to using specialist groups, supported employment and so on, 'trapping' people (Estroff, 1981) outside mainstream social justice, mirroring the findings of Barham and Hayward (1991). This was the logical outcome of a structural norm in which to thrive in the mainstream, socially valued world requires presenting as a particular type of person, a person they were not currently able to be due to the combined working of the three layers of Conversion Factor against them.

Chapter seven finished with an analysis of how the experience of mental distress interacted with education, work and income, socially valued domains of life in which macro-level data suggest that people with mental distress tend to experience particular social injustice (Chapter two). Specialised education could be helpful for generating increased capabilities but converting these into socially valued functionings was harder, some people being on a roundabout of supported employment and specialised education. The data on income begged a question about how many social norms people on benefits should be expected to forego before they cross a threshold domain in which they transgress the dignity of their society. This engages with Sen's argument that local conventions of dignity may include particular standards of clothing or 'other visible consumption' (1999, p.71; 2010, p.255), and that 'the commodity requirements of these general functionings are much more demanding in a country where people standardly use a bigger basket of diverse commodities' (1992, p.116). Very ordinary functionings - being able to go to group activities, have peace of mind, enjoy family life, or have secure housing - were seen to be breached due to the problems of low income and an 'activating' benefit system.

The data revealed injustices resulting from dominant norms in the context of employment. Nussbaum's (2006) argument that tightly structured employment markets exclude disabled people held true, explaining how people with mental distress remain structurally excluded from that socially valued functioning. But Sayer's reminder (2012) that satisfying work is unequally structured and that unequal divisions of labour are a major cause of capability inequalities, is a helpful structural explanation to understanding the outcomes seen.

Gary's case showed how sufficient stability or equilibrium is needed to allow the possibility of capability sets to be expanded beyond managing mental distress, but as his experience showed, pressure from the state to take up employment can disrupt this. In contrast, having a profession, and the education that went with this, supported the capability to assert agency, widen the capability set, and pursue valued functionings: thriving characteristics. If alienating labour is more socially valued than non-alienated participation in a group for people with disrupted lives, when work becomes the measure of recovery, this condemns society to a future of driving people to mental distress (James, 2008). This capabilities study has distinguished socially valued activities (Hopper, 2007, p.874) from personally valued activities. This distinction helps to reframe the social justice question about how lives lived outside the dominant norm might become valued. Capabilities helps us to ask this old normative-ethical question in a new way: how can dominant norms be changed to enable the personally valued to become socially valued, so allowing people socially positioned as surviving or 'being outside', and living with social injustice, to become socially valued, and so to thrive? If Conversion Factors and conceptions of social value operated along a more critical set of normative lines might this aid explanation - and intervention - based on a capabilities approach?

#### **9.2.4 Chapter eight**

If the first three data chapters approached the research questions in an open, exploratory, Senian manner, Chapter eight, 'Social justice re-worked: the domains approach to capabilities' used a combination of Nussbaum (2006) and Burchardt and Vizard's (2011) list of central human capabilities, or domains. It applied these as both a second angle through which to explore participants' experiences of social justice using capabilities, and to address some

contemporary questions in capabilities about the application of the domains framework from the perspective of people with mental distress, an empirical gap in capabilities literature. The findings were discussed in detail at the end of Chapter eight.

In brief, the Chapter found that all participants, even those with thriving characteristics, had experienced thresholds being breached, sometimes in multiple domains, a measure of the social injustice experienced by the sample, revealed using Nussbaum's framework as a method. This method also revealed very specific propositions from participants that would contribute towards a 'new normative' - social changes that may allow people with mental distress to enable their threshold domains to be upheld and therefore their social justice underpinned. These included better legal protection at work; more participation and agency in psychiatric treatment; meaningful and valued activities beyond employment that allow equilibrium and, underpinning the critique of Sen in the last section, enabling the personally valued to also be socially valued including through security of income. So, applying the model drew out suggestions for practical change in areas of life in which people with mental distress experience social injustice, also demonstrating the compatibility of Nussbaum's domains model with Sen's concern for pragmatic over ideal forms of justice (2010).

The domains method also led to participants critiquing the domains model itself, notably adding concern that the domains risked missing issues of interdependence, spirituality, connection, moral concern for the unknown other, and a deeper essence to human life. Participants also critiqued the notion of independence included in the domains, and the domains' subjectivity and individualised approach. They identified the clustering of disadvantage and fertile functionings, including in relation to health, in common with Wolff and deShalit (2007), re-affirming the evidence that interpreting social justice using the domains can be compatible with what is known about the social determinants of mental distress.

This Chapter's original contributions were: successfully applying the domains approach to a new population group; gaining critiques of the domains model by a new population group; and demonstrating the benefits and limits of the threshold/domains method in both interpreting social justice and in practically

proposing interventions that may support the social justice of this population group. However, whilst the domains provided a helpful framework for interpreting participants' subjective experiences, an understanding of macro-level outcome data and an analysis of the structural context are also required to achieve a fuller explanation of social justice outcomes, so minimising the risks of subjectivity and 'naïve positivism', and the risk of the domains approach reflecting the further capabilities concept of adaptive preferences.

In the concluding sections of this study, methodological and theoretical findings are explained followed by an analysis within a critical realist framework.

## **9.3 Methodological and theoretical findings**

This section specifies how using capabilities to interpret social justice in this study has enabled critique of existing concepts and normative assumptions from social understandings of mental distress, and shows how using capabilities as an analytical framework for empirical data in this study has allowed critique of concepts central to the capabilities approach.

### **9.3.1 Using capabilities with sociology as a research method**

Capabilities concepts were used to structure the empirical work, and the analysis demonstrated that capabilities can be operationalised and interpreted in small-scale qualitative research. The capabilities principles of heterogeneity and agency enabled the diversity of experiences of people with mental distress to be reflected. Whilst the subjective experience of mental distress was shown to matter to people, it was neither a singular experience nor necessarily held 'master status', getting beyond assumptions of stigma-based research and the problem of survivor-influenced analyses that are not transparent about lived experience, into the science of demonstrating attributes. Survivor-influenced literature tends to make the empirical opaque within the theoretical. This study has openly engaged the two, and both angles are needed to explain how agency operates.

Drawing general conclusions about social justice outcomes based on exploration of individual experiences using an established methodological approach in

qualitative sociological studies was an original element of the study in a capabilities context. This led to a number of analytical advantages over other approaches to evaluating the lived experiences of people with mental distress. By exploring social justice experiences both within and beyond the mental health system and applying capabilities as an expansive analytical framework, experiences of mental distress were re-located into the general social experience. This has led to a reconceptualisation of how we might not only understand the lived experience of mental distress, but a normative understanding of how this experience does or does not relate to social justice outcomes. This has demonstrated that capabilities concepts are compatible with sociological analysis and that capabilities analysis is compatible with social and structural determinants of mental distress, or the “‘maddening’ world” (Beresford, 2010, p.5), whilst bringing in agency. Evaluating social justice in terms of ‘what people are actually able to do and be’ (Nussbaum, 2006, p.70) has enabled analysis of the lives of people with mental distress to get beyond, for example, service usage as a metric. It has reinforced critiques of medical models of understanding, showing that social justice outcomes cannot be explained by differences in mental distress alone - a fuller explanation is needed. But, by using critical realism as the underpinning ontology, it has also challenged and expanded, without rejecting: symbolic interactionist overemphasis on the interpersonal; constructivist foci on labelling; functionalist assumptions of the ‘sick role’; historical-structuralist analysis that misses the agency of people with experience of the psychiatric system; and survivor-influenced studies that place the psychiatric system at the centre of injustice and which can omit from analysis the potential subjective impact of mental distress.

At the same time, the integration of sociological theory has enabled a critical approach to capabilities itself, whilst demonstrating the operationalisability of capabilities in theoretically informed, qualitative sociological studies, engaging the concern of Holmwood (2013) about the lacunae between the two.

### **9.3.2 Conversion Factors re-examined**

The study has addressed how various dimensions of living with experience of mental distress impact on the social justice of participants. In particular it has explained how social relations for people with thriving and surviving



characteristics within the rubric ‘people with mental distress’ are structured through the interplay of structural, social and personal Conversion Factors.

Personal Conversion Factors include the experience of subjective mental distress. Social Conversion Factors are those institutional and organisational features that may facilitate or constrain social justice, including the mental health system (hospital, mental health laws, diagnoses, medication, human support), and social institutions such as employment, income, education, family, intimate and wider social relations. Structural Conversion Factors, a significant sociological contribution to this study, are the market system, capitalist-based social relations, and social determinants of mental distress, plus the dominant norms and values that structure the way in which people interpret the world and shape what is socially valued in the world, notably including in this context the dominant norm of medicalisation of mental distress. So these norms and values lead to certain behaviours becoming defined as ‘mental disorders’ and subject to medical treatment in the prevailing psychiatric system. They also include wider dominant social valuations, that, for example, employment is good; particular lifestyles are valuable; the medical system is to be trusted, and so on.

Conversion Factors affect people with mental distress in multiple, layered ways prior to their distress experience and engagement with the mental health system, so are compatible with social determinants of mental distress. They also impact during experiences of mental distress, shaping responses from society and the mental health system, and afterwards, shaping the social justice that people may achieve once they have experienced mental distress and the mental health system. They have therefore been found to be compatible with social determinants of mental distress, as proposed in Chapter three.

The study demonstrated how Conversion Factors can operate positively together to enable socially advantaged groups with experience of psychiatric hospital to gain more accessible and more substantive opportunities to achieve a more socially valued capability set, and so social justice. Less previously advantaged groups with experience of psychiatric hospital have fewer substantive opportunities to achieve a socially valued capability set, so instead may achieve personally valued outcomes, so tending to trap people in social injustice.

So through this analysis we can hypothesise as follows. In a given geographical area, such as Glasgow, the more negatively predisposing the social and structural Conversion Factors, the nearer the ‘tipping point’ or precipitant for experiencing mental distress is likely to be, reflecting the evidence on social determinants of mental distress. The more extreme the experience of mental distress, the harder it will be for those people to overcome the negative social and structural Conversion Factors that influenced mental distress in the first instance, and to gain a socially just life beyond that: a *steeper and longer* Capability Gradient (adapted from opportunity gradient, Hopper, 2009, p.874; Wallcraft, 2010).

However, as capabilities maintains non-determinism, it allows that some people likely to experience social injustice may have personal Conversion Factors that enable them to enter a socially valued, thriving life, and vice-versa. The interplay of the three Conversion Factors, as also emphasised by Venkatapuram’s (2011, pp.154-155) critique of Nussbaum, explains how social structuring shapes social relations, advantaging those with mental distress from a socially valued, thriving background to re-enter socially valued relations. This, importantly, takes analysis beyond mental distress as the determining characteristic for what people are able to do and be, critiquing the biomedical literature. The data suggests that mental distress does play a role in how disrupted agency is (Tew, 2011) - it cannot be removed from the equation. But wider influences require attention too.

Applying the concepts in this context, using sociology, meant that the study was able to suggest an enhanced version of Conversion Factors, making contributions and holding constraints as below.

### **9.3.2.1 The analytical expansion offered by structural Conversion Factors**

The introduction of the original, extending concept of structural Conversion Factors enables empirical analysis to address the problem, identified in critical capabilities literature, of dominant norms and social ordering being missed in capabilities analyses. Structural Conversion Factors cannot be simply operationalised. But incorporating them into analysis pushes capabilities towards a more critical understanding of: the determinants of social justice for people

with mental distress; how and why certain roles are not socially valued; and informs choices about where to apply social pressure to maximise social justice for people experiencing oppression, creating a critique of Sen's limit of 'remediable injustices' (Sen, 2010, p.vii) which places too high a risk of what might be called non-remediable injustices continuing, lacking a full enough analysis.

These findings correspond with critiques made in other contexts of capabilities' neglect of structural contexts and overreliance on personal Conversion Factors. For example Orton (2011) on employment critiques the risk of a focus on the psychological remaking of the self, and Sayer (2012, p.5) critiques the capabilities-based Equalities Review (2007) in similar terms:

...it ignores structural external conditions and treats inequality as an accidental residual feature of British society, caused simply by prejudice, stereotyping, inadequate policies and 'complacency'. Its understanding of the structural causes of inequality is lamentable.

So, as a minimum, the inclusion of structural Conversion Factors enables us to ask harder questions of the social and economic system, achieving a more critical capabilities approach.

Structural Conversion Factors are also suggested as a more relevant and sociologically more cogent means than environmental Conversion Factors to explore the complexity of social justice specifically in western societies. Whilst determinants of mental distress in western societies may include the predominantly environmental in very particular cases, for example emotional hurt due to extreme flooding in particular regions, the general case is that environmental determinants in western societies are essentially social-structural, for example poor housing, stressful environments and so on. To express these as environmental Conversion Factors is potentially to miss modes of explanation that underpin the environmental as a second-order explanation.

The incorporation of structural Conversion Factors into the analysis has also enabled a least reductive interpretation of social determinants of mental distress. The study has highlighted, for example, the power of the medical model in constraining agency over treatment choices, and the role of dominant

cultural discourses, for example that paid employment is good, in sometimes negatively shaping the capabilities of participants, and so their social justice outcomes.

#### **9.3.2.2 Improving specification of relations between Conversion Factors**

This study helps capabilities to more carefully and critically consider discriminant issues in Conversion Factors. For example what are and should be social, what are and should be personal, and what is the interplay between the two? What are relevant structural Conversion Factors and how do these interact with and influence personal and social Conversion Factors? The introduction of structural Conversion Factors has the potential to enable greater specificity of these multiple layers for heuristic analysis, in particular by enabling a distinction between social and structural dimensions, so lightening the analytical load on social Conversion Factors.

#### **9.3.2.3 Conversion Factors can critique the dominant recovery model**

This analysis shows that people can live well and be socially valued after psychiatric hospital, but that those with positive social and structural Conversion Factors have an advantage in gaining socially valued roles (Hopper, 2007) and so social justice. This also begins to suggest an original explanation for the weakness of the contemporary recovery model (Chapter two) in changing the lives of those most distanced from social justice, and of other public interventions that focus on personal Conversion Factors. Achieving social justice for people with mental distress requires interventions that address the social and structural as well as the personal. Conversion Factors therefore become a practical tool to critique recovery, the dominant contemporary concept used in social policy and practice towards people with mental distress.

#### **9.3.2.4 Constraints to Conversion Factors applied as a method**

This study has shown that personal and social Conversion Factors can be operationalised and applied in qualitative capabilities studies. However, the study has left some problems unresolved and for further research beyond this thesis. First, more specific analysis of how the three types of Conversion Factor are weighted, bringing a new question into the longstanding capabilities debate

about weighting domains (e.g. Wolff and deShalit, 2007; Riddle, 2014). Second, to what level of exhaustion Conversion Factors need to be analysed in order to sufficiently evaluate social justice. Third, whilst structural Conversion Factors have not been allowed to escape analysis in this study, so gaining a fuller sense of how social justice outcomes are shaped, structural Conversion Factors are more complex to operationalise, leaving more theoretical and empirical work to be done.

### **9.3.3 The analytical implications of characteristics of surviving, thriving and being outside**

Applying the capabilities approach to interpret the lived experiences of people with mental distress has allowed the development of three characteristic experiences of social justice for people with mental distress: surviving, thriving and being outside, all of which may be experienced by a single individual in different domains or at different times. These enable a capabilities contribution to the survivor-influenced literature and the politics of terminology for people with mental distress (Chapters one and two). As seen below, surviving characteristics are reconceptualised from the user-led notion of ‘survivor’, avoiding ascription of the survivor ‘label’ by activists to others, becoming more participatory and more empirically accurate; ‘being outside’ provides for those that take actions that challenge dominant norms within or outside the psychiatric system; and thriving characteristics takes account of those that can meaningfully fulfil the dominant norm of ‘recovery’.

People with generally negative or mixed personal, social and structural Conversion Factors tended to have surviving characteristics. Life before and after psychiatric hospital tended to be an ongoing complex struggle, experiencing social injustice when trying to conform to dominant social norms. They tended to have a lower level of education or still be in higher education, to have ongoing problematic mental distress experiences and ongoing contact with the statutory and voluntary mental health systems, using different psychiatric medications of varying effectiveness and iatrogenic effects. They tended to use mental health groups. Due to social ordering and the power of dominant social norms around mental health, they tended to lack socially valued activities such as employment, could have difficult everyday social relations, including with

family and intimate relations which may have precipitated and may re-stimulate mental distress, and had a lower income. They perceived prejudice and discrimination. Their social context inhibited them and their agency was thus constrained. This was the general experience of the sample. Surviving had two dimensions - surviving material mental distress and surviving the psychiatric system, broadening the dominant definition in survivor-influenced literature, in which the power to define is placed on the psychiatric system.

A smaller proportion of participants, with mainly positive personal, social and structural Conversion Factors tended to have thriving characteristics, able to 'recover' beyond the mental health system and their subjective mental distress and to re-enter dominant normative society. For them, life before psychiatric hospital was doing and being socially valued roles, in professional employment or having completed higher education. They remained involved in mainstream groups, not mental health groups, and had intimate and family relations that supported them to contextualise their mental distress, so minimising its impact on being and doing socially valued activities. They had fewer problems with medication efficacy or iatrogenic effects. They used reasonable adjustments and professional, individual support to maintain mainstream social relations. They perceived little prejudice and discrimination. They tended to be from a structural context that was socially valued and were supported socially and professionally, enabling them to maintain agency and recover a life, conforming to social norms, that was valued distinctively from their mental distress. People with thriving characteristics were the type of people that might be termed 'recovery role models' or perhaps modern 'poster children' for mental distress.<sup>13</sup>

A smaller proportion of participants also displayed characteristics of 'being outside'. People with some 'being outside' characteristics tended to have had some subjectively enjoyable experiences from their mental distress. This group would have surviving and thriving characteristics, but would express 'being outside' in certain domains, at certain times. This involved implicitly or explicitly questioning dominant social norms and seeking alternative paths, for example in relation to medication, hospitalisation or employment. In doing this,

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<sup>13</sup> e.g. [www.newstatesman.com/lifestyle/2013/10/not-every-mentally-ill-person-poster-child-mental-illness](http://www.newstatesman.com/lifestyle/2013/10/not-every-mentally-ill-person-poster-child-mental-illness), sourced 8 February 2015.

participants offered a critical commentary on the norms that shape mainstream understandings of socially valued activities. They reveal a conflict between enacting diversity, achieving social justice and breaching dominant social norms: a complex struggle.

In capabilities terms, whilst challenging generalisation about this social group, the analysis showed that most of the experiences of the sample were of surviving, meaning lacking socially valued activities and living with capability deprivation, and so experiencing social injustice. Occasionally they were of thriving, having a wider capability set and experiencing socially valued activities, and so realising social justice. Whilst surviving and thriving experiences happened within dominant social norms, the data also showed how some capabilities pursued by the sample were outside dominant social norms, these activities characterised as ‘being outside’, and being difficult to convert into functionings due to that very breaching. Whilst demonstrating agency in the sample, this also demonstrated how notions of diversity, fundamental in capabilities thinking, are shaped by dominant social norms, tending to reproduce social ordering that leads to differentials in social justice outcome. This showed how capabilities could critique sociological conceptualisations, but also how sociology can add a critical dimension to capabilities.

There are three immediate implications of this typology:

‘Being outside’ is a new conceptualisation for people with mental distress who implicitly or explicitly make an ontological or epistemological critique of the dominant understanding of mental distress, the mental health system and/or the dominant norms that govern the dominant ontology and epistemology of mental distress and the mental health system.

The thesis is therefore that there is not a ‘group of outsiders’ that critique everything, wholly divided from a socially conformist majority with mental distress, but that people with surviving and people with thriving characteristics can critique dominant norms, so ‘being outside’ periodically. The thesis is also that people that tend towards surviving may thrive in certain domains, and vice-versa. This entangling of the three characteristic groups offers possibilities for

alliances to develop across all groups of people with mental distress, perhaps in relation to some particular domains, such as medical model treatments.

As all three reconceptualisations of people with mental distress were characteristics, not identities, this also has the potential advantage of averting essentialisation of people with mental distress, compatible with intersectional thinking, including as pursued by Sen (2006).

### **9.3.4 Combining sociology and capabilities reveals constraints in the sociology of mental distress**

A large part of the methodological contribution of the study was capturing in-depth qualitative data about subjective experience of mental distress and the mental health system using capabilities concepts. This revealed a number of constraints in sociological understanding of mental distress.

In contrast to studies that tend towards minimising diverse empirical experiences and agency, resulting in an overstructured understanding, such as survivor-influenced studies and structuralist studies (Chapter two), capabilities strongly incorporates agency. As a result, subjective mental distress is able to be incorporated into the analysis when it appears, without medicalising or labelling it, nor minimising it, leading to a less reductive account than those which focus on oppression within the psychiatric system. Similarly, as capabilities views early death, spoken to strongly in the suicide data, as the ultimate form of social injustice, it can also explore this and make it part of the central analysis.

In relation to the social constructivist and symbolic interactionist tradition (Chapter two), the study found that structural forces are material, and that limiting explanations to the social situation as subjectively perceived by people would, in capabilities terms, risk reflecting adaptive preferences related to the power of dominant social norms. For example, the concept of stigma could only be critiqued and developed by bringing in structural explanations for different social positionings of participants, reinforcing Scambler's critique of Goffman (2006). Established assumptions in the sociology of mental distress of the impact of social stigma were muddled by the data, in a way which also advances Tew's (2011) model of the 'triple whammy' (experiencing mental distress,



experiencing stigma, then internalising stigma). For the two participants with the strongest thriving characteristics, discrimination and prejudice were perceived only as being marginal. This glimpse allows us to hypothesise that this is because for people from a more highly educated and professional background, discrimination and prejudice are less likely to have - and therefore be perceived as having - an impact on their socially valued status. In contrast for people with surviving characteristics, discrimination and prejudice were perceived as more central; their difficulty in establishing themselves in socially valued positions being most simply subjectively explained by discrimination and prejudice. However, explored sociologically, the objective explanatory factor is that, for example in the employment context, few socially valued roles exist in a capitalist structure (Sayer, 2012) and dominant norms are structured in such a way as to favour certain groups for these positions. The experience is not equal due to these structural Conversion Factors; discrimination and prejudice - stigma - are a social symptom of these.

The data suggests that subjective mental distress can be transgressive in the social world. This explains how some behaviours related to mental distress become subject to prejudice in part as they contravene social norms of behaviour (Scambler 2006). But mental distress is also socially shaped - influenced by predisposing and precipitating factors, including social relations, for example with family, partner or employment norms. Mental distress also socially shapes, for example to what extent people feel able to pursue mainstream activities, or provoking specific social responses from others, which may be prejudicial or inclusive. Subjective mental distress is therefore inherently social and cannot be detached from the social-structural context that enables or constrains agency to pursue socially valued activities. As Scambler (2006) suggests, two people with the same 'order' of mental distress may experience very different outcomes, related to the social relations in which their mental distress is expressed. In capabilities terms, Tew's mental distress as 'disruption of agency' therefore risks falling into the trap which Sayer (2012) identifies, and for which Venkatapuram (2012, p.154) critiques Nussbaum, of treating external conditions and internal capabilities as if they are discrete when they are complicit. The sociological argument and evidence employed in this thesis has demonstrated the need to maintain an agency-structure dualism.

## **9.4 Critical realist synthesis: towards a critical capabilities model of mental distress**

Sociology and capabilities, as two compatible, intertwining, normative modes of understanding the lived experience of mental distress have combined to provide a multilayered interpretation of participants' descriptions of the material internal experience of distress, how these experiences affect and are affected by direct interactions in the social world, the multiple ways in which agency is used in this context to negotiate social structures, and the influence of underpinning social structures, powers and mechanisms shaping the dominant social order, virtually beyond perception. Together these laminates, which combine a material base to existence with almost imperceptible shaping through social structures, give tendencies to social justice outcomes, and must in the end be integrated using a critical realist analysis so providing a least reductive model of the determinants that shape social justice for people with mental distress. This is the theoretical foundation of a critical capabilities model of mental distress.

Consistently with Porpora (1998), Bhaskar and Danermark argue that using critical realism as an ontological and epistemological approach enables the construction of a 'coherent narrative that maximises explanatory power' (2006, p.292) - just as the capabilities approach aims to 'encompass all the previous models' in understanding the complexity of disability (Dubois and Trani, 2009, p.197). Critical realism is further compatible with a capabilities analysis because of their shared normative concern for how lives are actually lived, or what people are disposed to be and do (Bhaskar, 1979, p.123), and to their shared normative purpose of explaining social injustice for the purpose of human emancipation (Watson, 2012, p.102). They mutually understand the world as non-determined, with humans reflexively taking actions in response to structural tendencies, with the potential to comply or subvert as seen in this study.

This study has found limitations in structural, survivor-influenced, social constructivist and symbolic interactionist methodologies of sociological research into mental distress and in applications of capabilities to understand lived experience. These each avoid diverse difficult areas - or 'essential complexity' (Bhaskar and Danermark, 2006, p.295). Capabilities also demotes analysis of the

structural, or non-remediable (from Sen, 2010, p.vii) dimension, to which structural sociological approaches draw attention. This suggests an opportunity to apply Bhaskar and Danermark's framework in the context of mental distress and social justice, and to aim for a least reductive understanding, unifying capabilities and sociological research.

In the introduction, Silverman (2005, pp.97-98) reminded us that models '...tell us what reality is like and the basic elements it contains ('ontology') and what is the nature and status of knowledge ('epistemology')'. Models have been demonstrated in this study as of particular significance as they frame the way in which people with experience of mental distress are understood and treated, medically and socially. This section makes a final original contribution by starting to lay out the elements that constitute a critical realist model of reality, and how it is explained for people with mental distress using capabilities approach concepts, seeking a least reductionist account.

The development of a tentative critical capabilities model of mental distress, adding explanatory theory of causation to the conceptualisation of lived experiences of mental distress that capabilities has enabled, needs to incorporate: a. the normative approach of capabilities to conceptualise and reduce social injustice; b. a sociological analysis of the world as experienced by people with mental distress; c. an understanding of the importance of underlying structures to explanation of social justice outcomes as accounted for through a critical realist account. Thus the analysis can causally link the lived experiences of people with mental distress and their practical decisions with the context in which those lives are lived.

So, what might a critical capabilities model of mental distress look like?

Adapting the approach of Bhaskar and Danermark suggests using a necessarily laminated system (2006, pp.288-290). In an open and emergent system, these four laminates explain non-determined outcomes incorporating tendencies and counter-tendencies towards social justice or social injustice for different people with mental distress:

**a. Social ordering** from the values of the Enlightenment, Social Contract and capitalism leads to a dominant normative position of certain social roles being

highly valued, most notably paid employment, and others poorly valued, such as experiencing mental distress. This results in a tendency towards a state of social experience for people with mental distress as follows:

**b. Dominant norms** that value certain people and practices, as expressed in this context through: a. the psychiatric system (medical conceptualisation of distress, notions of rationality/irrationality, professional powers to define and constrain, legal underpinning); b. the economic system (valued employees, profitability, predictability, risk aversion, legally underpinned). This tends to result in:

**c. Social practices** that operationalise this through: a. a medical system, laws and guidance, medication and diagnosis, community care, recovery; b. an economic system that prioritises certain groups for valued employment. These are underpinned by governing practices that lead to the internalisation of employment as socially valued and the psychiatric system as necessary. Within this there is also:

**d. A bio-psycho-social reality** of a. mental distress (non-determined yet material, with strong correlations with social determinants which tend to socially order people through the above laminates); and b. agency (autonomous, yet also shaped by a. b. c. above).

These laminates together explain tendencies towards social injustice, or characteristics of surviving, for people with mental distress as discovered in the empirical data in this study. Due to the incorporation of the mutual critical realist and capabilities principles of agency and non-determinism, the conceptualisation also allows for people to have characteristics of thriving or of 'being outside'.

Bhaskar and Danermark suggest seven further, also laminated dimensions (2006, pp.288-289): physical, biological, psychological, psycho-social, socio-economic, cultural, and normative elements. These elements 'are all essential to the understanding of the phenomena in fields such as disability research' (2006, p.289). These provide a fuller explanation of tendencies towards social injustice for people with mental distress and in the present study these map onto

personal, social and structural Conversion Factors, reinforcing the potential for explanatory compatibility between capabilities and critical realism, as posited in Chapter three:

Structural Conversion Factors are equivalent to: socio-economic, cultural and normative elements (e.g. the way in which mental distress tends to be conceptualised in the world, and the social justice outcomes that tend to be reproduced as a result).

Social Conversion Factors are equivalent to: psycho-social elements (social provisions and social relations such as the mental health system and the family, tending to reproduce social justice outcomes).

Personal Conversion Factors are equivalent to: physical, biological, psychological elements (subjective mental distress and other dimensions held within the self, also materially influencing social justice outcomes).

As seen in this study, these elements constantly interact - structural and social, social and personal, and personal and structural, as people with mental distress - as for all humans - live in and interpret a world that was not of their making, yet which is now part of their making. The social justice outcomes of individuals will change over time, but with tendencies (Porpora, 1998; Bhaskar and Danermark, 2006), and across domains of human capability, as in the study findings.

## **9.5 Study limitations and future directions for research**

In terms of the method, two interviews were conducted with two thirds of participants, for some of whom some issues had changed in the intervening period. This shed new interpretive light on these dimensions of these participants' first interview data. This forces consideration of how adequate undertaking a single interview with one third of the participants was to draw the conclusions made from their data; although care was taken in interpretation, given more time for fieldwork an alternative method could have involved spending more time with people, giving them more time to reflect on their lives and on what they were able to do and be.

The data found was subjective, and no attempt was made to confirm peoples' accounts, although the second interviews did provide an opportunity to check certain points with participants. In particular, there was no reliable means of comparing the depth or character of peoples' subjective experiences of mental distress. Whilst this was justified by the evidence that social factors play a substantial role in shaping mental distress and social justice outcomes, and the evidence that experiences of mental distress were highly individual and therefore hard to compare, the question of the degree to which explanation of differential social justice outcomes may have correlated with subjective intensity of mental distress could not be established beyond peoples' personal descriptions of their experiences. This is indicative of a methodological tension in seeking to empirically evaluate social justice experiences at the individual level, so seeing through the capabilities principle of treating individuals-as-ends, which this study has conducted. This merits further empirical research to further explore this analytical tension between the individual and the social in the capabilities approach.

In terms of sampling, the sample was small, achieving strong theoretical generalisation, and very tentative empirical generalisation. This reflects the persistent tension in social research between depth of understanding and breadth of generalisation (e.g. Silverman, 2005). Glasgow is also not representative of 'western societies' or of urban life in Britain in general, so other geographical areas may have different findings from replicating the study. Ethnic minority groups were missing from the sample, despite attempts to recruit, further limiting the generalisability of the findings. A future study could replicate the methods used and focus on, for example, a sample of people likely on the basis of Conversion Factors to have strong thriving characteristics, and to empirically explore the diversity of social justice outcomes, to test the model developed further. The transparency of the account makes this straightforward.

In terms of reflexivity, my role as framer, interviewer and interpreter of the data have fundamentally shaped the study findings. The interpretation of data is my own, influenced by the multiple frames used to interpret the data, yet this potentially is in conflict with the original aim of conducting the research with respect to the value base set out in Tew et al (2006). However, the essence of the study was to take a social rather than medical interpretative approach, and

to treat participants as fully rounded human beings, with lives both affected by and beyond their distress experience and their experience of the mental health system. So, essentialisation was minimised throughout, the diversity of voices of participants facilitated and written. The influence of participants could have been improved through stronger respondent validation through the research process.

In terms of a further values-based ethic to the study, participants were promised a summary of the research findings, as were the voluntary organisations that helped to advertise the study. These will happen, maintaining some accountability to participants and to people advocating within the sector.

## **9.6 How to take thesis forward**

Areas of lived experience that were in the data but not selected due to space requirements and which would be of particular interest for further analysis were the role of volunteering and its relationship with capabilities and social justice, and the role of friends as social Conversion Factors. There were several other ways in which the thesis could be usefully progressed.

Empirically the study can be replicated in the same or different geographical areas and with the same or different population groups, treating them in the same way as a potentially diverse social group, so avoiding essentialisation.

Methodologically, the study has demonstrated compatibility between a sociological approach and a capabilities approach. The study has shown that within capabilities, whilst requiring caution, a Senian approach can be operationalised, as can Nussbaum's domains approach.

Normatively it has demonstrated compatibility between critical realism and capabilities in terms of framing an analysis of how social injustice tendencies occur for this social group, posited in the tentative critical capabilities model of mental distress which could be further developed.

Theoretically the combination of capabilities with sociological theory and specifically critical realism can be explored further.

Substantively, in terms of improving policy and practice towards social justice for people with mental distress, the study has first argued that this can best be understood by considering what people are actually able to do and be. Second, it has demonstrated that the dominant policy notion of recovery is too individualised to achieve social justice for people with mental distress, and needs to be reconceptualised to include the social and structural Conversion Factors that shape social justice outcomes. In the area of personally valued versus socially valued activities the study findings could be used, for example, in conjunction with Olin Wright's work on a citizen's income (e.g. 2006), which opens up the possibility for personally valued activities to become socially recognised as part of an ethical programme to enhance human flourishing, reflecting the needs of many of the social group in this study to achieve equilibrium and so social justice.

In terms of developing capacity for action to achieve social justice by people with mental distress themselves, or emancipatory purpose (Tew et al, 2006, p.vi) the study has demonstrated a number of possible outlets and means for this, whilst having regard for the limits of generalisability of the study. It has shown how agency exists for people with mental distress; demonstrated how people can 'be outside' dominant norms; revealed injustices within the mental health system, notably in hospitals; confirmed the social construction of diagnoses and the unpredictability of psychiatric medication; and has taken the movement beyond 'stigma' as an explanation for social injustice. It has shown that injustices are due to far more than prejudice and discrimination, and the rubric of 'stigma' can distract from a more empirically-informed focus on the dominant social ordering that shapes tendencies towards social injustice.

## **9.7 Conclusion**

This study has attempted to reconceptualise mental distress within a social framework. The findings have provided evidence that mental distress can be experienced positively, but primarily in this study, negatively. They have also demonstrated how the mental health system interacts with subjective mental distress from the perspective of those with distress experiences, and how participants then incorporate that overall mental distress experience as part of



their lives, in the context of dominant social norms which tend to act against their social justice.

The study has shown that qualitative analysis using Conversion Factors can critique macro-level findings of social injustice for people with mental distress; showing how the degree of social justice achieved may vary. Using Conversion Factors this study has suggested how these differential outcomes happen.

The study has highlighted the impact of the dominant social order on social justice, demonstrating how the enactment of non-conscious structural norms, for example through the mental health system and laws or through employment norms, impact on personal social justice outcomes. The study has therefore provided an anti-individualisation thesis, bringing together the personal, social and structural. It has provided a fuller explanation of how social injustice tends to happen through the operation in society of non-conscious hierarchies of socially valued people and practices.

The thesis has created a sociological analysis of how people with mental distress experience mental distress as a material reality, not a social construction; how mental health services can maintain life by constraining what people are able to do and be, whilst reflecting wider social injustice; and how wider activities in life, such as family, intimacy and work also shape and reflect social justice in diverse ways for people with mental distress. Through its empirical data, the study has challenged assumptions of the survivor movement which imply that mental health services are invariably problematic, and literature that suggests that stigma is the dominant social experience that shapes social justice. It has explained how the Foucauldian power of dominant social norms operate in this context, but once placed within a critical realist framework, has demonstrated and explained how outcomes are only partially determined. This was reflected in the analysis that participants with experience of psychiatric hospital generally had characteristics of surviving, but some had characteristics of thriving, and some of both groups also demonstrated characteristics of 'being outside' in particular domains, or in particular contexts.

In normative terms the data suggests that social justice for people with mental distress might be better achieved in three ways - by minimising the impact and

occurrence of social determinants (predispositions and precipitants) of mental distress (e.g. violence, stress, abuse); by providing a much wider range of non-hospital-based support, care and protection opportunities for those who continue to experience mental distress, so that life and dignity may be maintained with greater agency; and by changing social norms to achieve social justice for those who experience mental distress but who still do not fit within the contemporary dominant norm. These are compatible with Plumb's (1994; 2012) conception of social explanation, protection and norm-changing; and with post-psychiatry's contemporary critique of medicalised processes of constraint, diagnosis, and medical treatment.

This study has highlighted the unfulfilled critical potential of capabilities which tends to underplay the structural dimension, on the one hand; and the critical advantages of conflict theory-based structuralist literature, which tends to underestimate the personal dimension on the other. It has shown how Conversion Factors, developed to incorporate the structural dimension, can be applied to construct an analytical bridge between the two fields of study in the context of applied qualitative research in mental distress.

Jan Wallcraft (2010) noted that capabilities might be used to develop an understanding of 'the subtle ways in which we are damaged and disabled by psychiatric labelling, treatment, compulsion or even the threat of these' and that it:

...could be used to describe and measure how the original cause of difference - whether this is seen as resulting from a trauma, dissent from social norms or a 'mental disease' process - is converted to a disability or a 'capability deprivation.

This study has shown that whilst capabilities can be applied to explore these questions, and indeed demonstrate the tendencies that Wallcraft identifies, it is capable of a much broader analysis of the lives of people with mental distress.

Finally, the data exemplify how personal, social and structural Conversion Factors may also operate in systems of power to shape social justice for other social groups. The findings suggest, for example, how agency may be structured in contexts not only of the psychiatrist and the mental health system, but of the

doctor and the health service, teacher and the schooling system, police officer and the law, unemployed person and employment officer, Ministers and the ideologies of the churches, and so on, revealing the way in which the professional follows the institutional norm, which in turn broadly reflects the dominant structuring of society, leading to the patterning of social justice outcomes. Yet it also demonstrates that groups facing this structural oppression still hold some agency, showing how some people become structured into actions that are 'being outside'. This suggests a path towards making a general conclusion drawn from the experiences of the social group that were the focus of this study, people with mental distress.

# Appendices

## Appendix 1 – recruitment call



### **Research study: Exploring the lived experience of people with mental distress**

I am a former mental health advocate, now studying at Glasgow University. I am looking for people to take part in a study about what life is like for people who have used psychiatric services. I am interested in hearing about where you live, how you spend your time, and how your experience of using psychiatric services might have affected the choices you make in life. This is social research not medical research. If you fit the following profile I would love to hear from you:

- You have spent some time on a psychiatric ward since January 2006
- You are not currently on a Community Treatment Order
- You may still use psychiatric services, or may see yourself as 'recovered'
- You live in Glasgow
- You are over 18 and under 65

If this is of interest to you, please email, write, text or call me on the number below. I will give you more information. If you are selected to take part, I would like to interview you twice over the next six months, for about one hour each time. Expenses will be paid and I will provide refreshments. Everyone who participates will be given a summary of the research findings, as will the voluntary organisations that have helped to advertise the study. All participants will be made anonymous in publications that result from the research.

I hope that this study will be a good opportunity to hear about the lives of people who have been users of psychiatric services.

### **Richard Brunner**

Postgraduate Research Student

Strathclyde Centre for Disability Research

School of Social and Political Sciences

University of Glasgow, Glasgow G12 8RT

Telephone: 07423 182719

Email: [r.brunner.1@research.gla.ac.uk](mailto:r.brunner.1@research.gla.ac.uk)

## Appendix 2 – Plain Language Sheet

### Participant Information Sheet

#### What is this study about?

My study aims to understand quality of life for people in Glasgow who have been in psychiatric hospital at any time since 1 January 2006 under a Community Treatment Order. I would like to talk to people individually about what they are able to do in daily life, and what they would like to be able to do, about what helps them to live the life that they want, and any barriers that they face in being able to do this. The study is as much about friendship, neighbourliness, family, financial security, meaningful opportunities, feeling valued and making choices as it is about paid support and mental health services. It is about you and your life.

#### Who can take part?

I am seeking people:

- Who have been in psychiatric hospital at any time since 1 January 2006 under a Community Treatment Order; **and**
- Who live independently (but may have drop-in support at home); **and**
- Who live in Glasgow.

#### What does it involve?

Two meetings. First, I will interview you on your own for about 90 minutes to talk together about your daily life. Four to six months later I will meet you again for about 90 minutes to talk about what has happened in your life since our first meeting. We will agree together where the meetings take place - it may be in your home, at a centre or group that you like using, or here at the University. Because the discussion is about your life it will need to be in a confidential room. With your consent, I would like to record our conversations, so that I can type up what we

said for analysis. **Participants will receive any expenses, and refreshments will be provided.**

## Appendix 3 – consent form



### Consent Form

**Title of Project:** Exploring the lived experiences of people with mental distress

**Name of Researcher:** Richard Brunner

1. I confirm that I have read and understand the Plain Language Statement for the above study and have had the opportunity to ask questions.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.
3. I consent / do not consent (delete as applicable) to the interviews being audiorecorded.
4. I understand that my name and any other personally identifying data will be removed in any publications arising from the research.
5. I consent / do not consent (delete as applicable) to my interviews having all personally identifying features removed and being offered to the Economic and Social Data Service for archiving.
6. I agree / do not agree (delete as applicable) to take part in the above study.

_____	_____	_____
Name of Participant	Date	Signature
_____	_____	_____
Researcher	Date	Signature

## Appendix 4 – example interview two email

On 26 Sep 2013, at 12:39, "Richard Brunner" <r.brunner.1@research.gla.ac.uk> wrote:

Hello X,

I hope you are well. You might remember the research interview that we did at Strathclyde University in March. I am just following that up.

You might recall that I said that I would like to interview each participant in the study twice. I am writing to ask if you would like to participate in a second interview. This discussion will probably be shorter than the first one. I would like to follow up one or two points from the first interview. I would also like to ask you some questions about a framework that attempts to understand the things that help people to thrive in life, to see what you think about it.

If you would be interested in taking part, the interview will be on your own again. With your agreement I would again like to record our conversation. As with the first interview, confidentiality will be limited to me and my supervisors (and a transcriber if used to type up your interview). All identifying features from the interview will again be removed in any publications.

I will send a summary of the findings of the research to everyone that participates in the study, whether or not they choose to take part in the second interview.

If you would like to take part, please reply to this email, or call or text me on 07404 093493 (new number). Then we can set up a date and time to meet. Next week



any time on Tue 1, Wed 2 or Thur 3 Oct look good for me at the moment, so do propose any time on those days if they are convenient for you, and I should be able to book us a suitable room.

I look forward to hearing from you.

Best wishes,

Richard.

Richard Brunner

Postgraduate Research Student

Institute of Health and Wellbeing and School of Social and Political Sciences

Strathclyde Centre for Disability Research

Room 204 Adam Smith Building

University of Glasgow

Glasgow G12 8RT

## Appendix 5 – round one interview guide

### Round one interview schedule

#### (i) First stage

**Pre-ample: ‘Stories are what I am interested in, so I might ask you to talk in detail about some specific experiences that you mention, and not others.’**

#### a. Interview questions

1. Can you tell me a bit about who you are, where you live, and what you generally do with your day? *(Optional prompts: How do you tend to spend your time? Tell me what you did yesterday. In what way was this a typical day? In a typical week – where are you? Who are you with? Who do you see? (prompts: friends/acquaintances, professionals, colleagues, family))?* Are you involved in any groups or organisations?)
2. Can you tell me a bit about your history in terms of mental health? *(prompts: subjective experiences of emotional distress, diagnosis/diagnoses, hospitalisations (may be several times), treatments and side-effects, discharges/aftercare, community support)*
3. Going back to your life now, of the things you currently do, what gives you most satisfaction? What are the most frustrating aspects? *(explore)*. [This discussion aims to **identify three or four good examples** that for the interviewee encapsulate the best and most challenging areas of their life. These are likely to involve examples that involve both beings and doings (people and activities). These may include work, education and volunteering; housing; safety; meaningful life relationships; participation in ‘political’ activity or community groups; the role of transport and day centres; money, the role of benefits and debt; caring relations (children and partners)].
4. How much choice do you feel you have about what you do in life? *(discuss ways in which interviewee is able to make choices, whether it has changed over time, in which area of life they feel most free, and in which most constrained)* Are there things that you would really like to be able to do that you can’t? *(optional prompts: e.g. would you like to change your living circumstances, job or education, psychiatric treatment? Take a holiday? Be spontaneous? Find companionship/friendship/love, have a family?)* What influences this? *(optional prompts: constraining roles of the psychiatric system, subjective feelings of distress, employers, benefits, income, housing (location, safety), physical health, family etc.)*.
5. Do you feel fairly treated as a member of society? *(prompt: in what ways yes and in what ways no?)* Do you/did you feel fairly treated by the mental health system? *(prompts e.g. by the mental health laws - able to use aspects of the Mental Health Act such as advance statement, advocacy,*

*legal representation at Tribunal?*). How far do you feel included in society or excluded? What tells you that?

6. How safe do you feel – both in the house and when you go out in the local area? What affects your feeling of safety? Does your psychiatric experience have an influence? If so, can you give any examples? (*prompts: examples of going out will arise in Q1. This Q will allow a picture of where a person feels safe to travel/'be', how far choices of where to go are constrained or enabled*). Do you feel protected by the police? (*prompt: any specific examples? Any relation to psychiatric experience?*) Do you ever have to adapt the way that you would really like to behave or the things that you do because other people wouldn't understand it or 'approve'? (*discuss*)
7. Is there anything else that is important to the quality of your life, or what you would like to choose to do, that you would like to talk about?

#### **b. Demographics**

8. Finally, can I check some points with you? I am collecting these so that people that read the research can understand the range of backgrounds of people that have taken part in the study (*check any of below that have not been made clear in the course of the interview*):
  - Current age
  - Ethnicity
  - Age of first hospitalisation
  - Number of hospitalisations
  - When last in hospital or subject to a Community Treatment Order as an outpatient
  - Current housing type
  - Educational level (options: Standard grade, higher grade, degree)
  - Employment status (options: mainstream job, supported employment, voluntary work, education, income support, sickness benefits, housing benefit)
  - Current contact with support services (statutory or voluntary sector), average time per week using these services.

That is great. Is there anything else that you need to say, or that you would like to ask?

## Appendix 6 - round two interview guide

### Round two interview schedule 05 July 2013

A. (*where applicable, see my notebook*) Can I check a couple of factual points with you from the last interview? (reminder of story, then direct questions). And/or: last time we met, you talked about [topic that they mentioned was ongoing]. What has happened since the interview about this?

B. Introduction: I would like to talk about an idea with you, it's about quality of life, and I would be really interested to hear what you make of it. Is that ok? (*If yes...*)

1. Some people say that everyone should have the right to live a life where they are really thriving and doing well - not just 'getting along ok' or just surviving day-to-day - and have real opportunities to do the things they really want to do and to lead a life that they value and choose to have. But people with experience of psychiatric hospital are sometimes said to find it difficult to be able to thrive. If I were to ask you about whether you are thriving or just 'getting by', what would you say? [*alternative wording*: How would you say you have you been doing (*captures past/present*) in terms of feeling that you are able to thrive (*flourish/do really well*) and have the chance to do the things that you really want to do?] (*sub-questions: press a little on past/present comparisons*)

2. These (show table) are like a recipe, a set of ingredients for a thriving life - not just a life where people are just getting along ok, but are able to do really well and leading a life that they would really value and choose to have, the life they really want. (*Optional metaphor: The ingredients not just for a cake or some bread that's ok, but the best bread or cake, that tastes really nice and that you really want*). The idea is that all of these are needed to live a thriving life. I would like to ask you some questions about them, and how important these are for you in your life. There are no right or wrong answers, no 'blinding insight is needed! I'm just interested in what you think about this in relation to your own life.

*Read through the capabilities diagram, taking time, giving examples where this helps (saving the Anything else box for later comment).*

3. Do these all make sense to you? Do you need me to explain any more about any of them? Do you have any questions about any of them? What do you make of them? *(results in discussion on clarifications, definitions and purpose in which the meaning of some of them might be discussed. 'Being healthy' esp interesting to discuss (good health? Physical? Mental? Free from stigma, discrimination, always treated with informed consent? Lifestyle? Environment? These meanings are all used by Burchardt and Vizard in their examples)*

Questions 4 and 5 may be reversed, dependent on whether 'most important' or 'least important' seems the most productive route given answers to Q3. *These Qs enable a focus on the extremes - most and least important domains. May be discussion about difficulty of choosing, or may result in some most vital and some least important. Discussion will include the way that they define those particular capabilities, and what it is about these particular dimensions that matter/don't matter to them. This may include reflection on issues in relation to their experience of/treatment for mental distress (or if not mentioned that lack of salience in itself would be significant). May also include dimensions of identity such as gender, age, sexuality, physical health, socio-economic position as 'master status'.*

4. Are some of these really important ingredients for you to have a life that you would value and would choose?

*(Optional sub-Questions: What is it that makes X more important to you (a particular experience perhaps?) Is it having the choice to do and be X that matters to you in living a thriving life, or actually doing it? How are you doing at the moment in terms of achieving those aspects? Have you always had that in your life, or have there been times when you have not had (access to) it? How could that aspect be secured for you? What would need to happen/change? (structural/social/economic, psychosocial/normative, impairment effects etc.) Whose responsibility is it? (e.g. self/social norms & attitudes/state/employers/politicians etc- get a sense of structure/agency dynamics and interactions:*

*Conversion Factors*). What about 'being healthy'? Is that vital to being able to thrive, for you, in your experience?

5. The opposite question - Do some of these strike you as being unimportant or less important ingredients for you to lead a thriving life? Which ones? What is it that makes X less important to you (a particular experience perhaps?)

6. (*Anything else* box) Is there anything else (*'other ingredients'*) that are important for you to be able to live well or thrive that is not on the list? (*explore*)

7. Is there anything else that's important to say about being able to thrive, or having the chances and opportunities to thrive that we've missed?

8. How would you now say you have you been doing (*captures past/present*) in terms of thriving (*flourishing/doing really well*) and having the chance to do the things that you really want to do? (*'informed return' to starting question*).

9. How was that for you? KEEP RECORDER ON FOR DISCUSSION (*enables them to say 'that was brilliant' or that was hard, that was meaningless etc. - a potential critique of process and capabilities, getting beyond the formal responses in interview*).

10. Thank you (*emphasise and reassure how useful their answers were in helping me to think about these issues. Just right etc*).

11. Check I have the right contact for them to send the summary of findings next year (hopefully).

## Appendix 7 – transcription confidentiality agreement



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### CONFIDENTIALITY AGREEMENT

#### Transcription Services

An exploration of how the capabilities approach may enhance understanding of lived experiences of mental distress

I, [NAME WITHELD], transcriber, agree to maintain full confidentiality in regards to any and all audiorecordings and documentation received from Richard Brunner related to his doctoral study. Furthermore, I agree:

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2. To not make copies of any audiorecordings or computerized files of the transcribed interview texts, unless specifically requested to do so by Richard Brunner;
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Date: 28 March 2013

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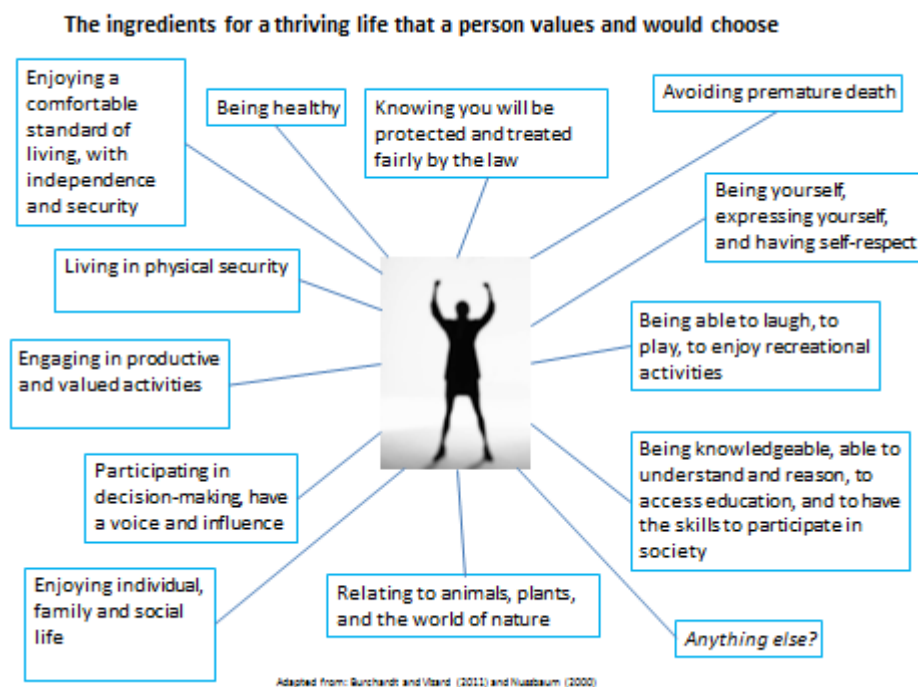
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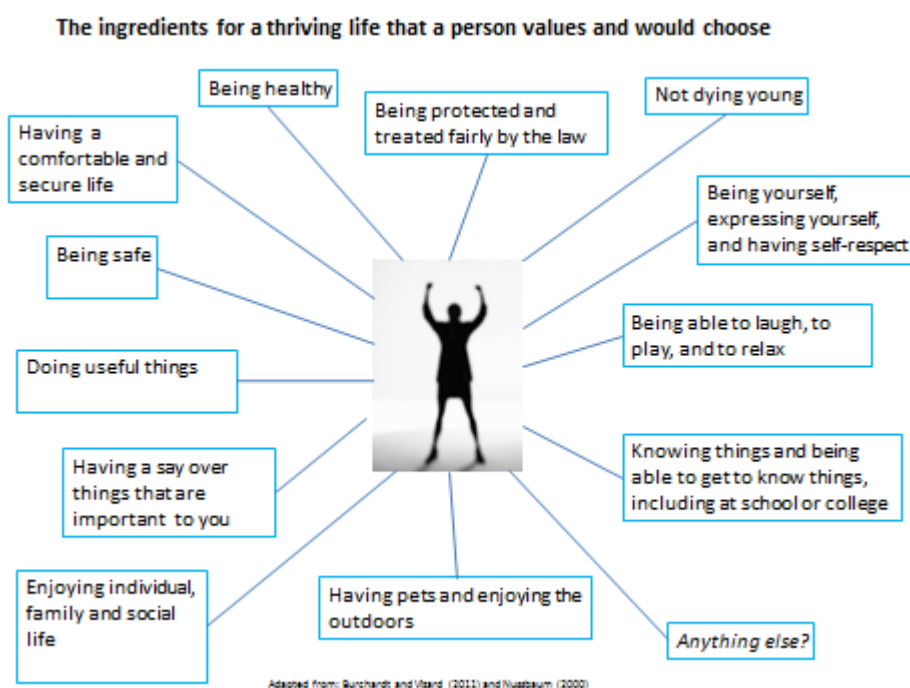
Email: [r.brunner.1@research.gla.ac.uk](mailto:r.brunner.1@research.gla.ac.uk)

## Appendix 8 – round two domains diagrams

Standard diagram:



Easy read diagram:





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